

**The psychosocial challenges and coping mechanisms of palliative care volunteer  
caregivers for people living with HIV and Aids.**

by

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Submitted in accordance with the requirements for the degree of

**MASTER OF SCIENCE**

in the subject

**PSYCHOLOGY**

at the

University of South Africa

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June 2014

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I declare that The psychosocial challenges and coping mechanisms of palliative care volunteer caregivers for people living with HIV and Aids is my own work and that all the sources that I have used or quoted have been indicated and acknowledged by means of complete references.

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DATE

## **ACKNOWLEDGEMENTS**

I would like to express my sincere appreciation and gratitude to:

The Almighty God for his strength, wisdom and guidance which has taken me this far.

My Supervisor, Prof A.C. Van Dyk, for her valuable support and encouragement; this study would not have been possible without her. I thank her for her tireless support and patience.

My Mentor, Carol Jansen, for her support and encouragement which kept me going during the toughest stages of the journey.

To Prof Levey, for his wonderful editorial work.

To the Management of Pfunekani Community Organisation and Umthombo-Wempilo Home-based care who gave me permission to conduct this research in their facilities.

To all the volunteer caregivers who participated in this study. Without them, this study would not have been possible.

To all my friends and Shalom Women's Prayer Group for their unwavering prayers, "Xikwembu xa endla masingita."

Finally, but most importantly, I dedicate this dissertation to my beloved husband Michael Mthombeni who gave me the courage to carry on when I felt like all inspiration had run dry, and my children Nyeleti, Nyiko, Shongile and Nhlanhla for their tolerance and understanding during the years of my studies.

## SUMMARY

South African palliative care volunteer caregivers play a crucial role in caring for people living with HIV and Aids, but frequently do not receive the support and respect that they deserve. The current study explored the psychosocial challenges and coping mechanisms of palliative care volunteer caregivers for people living with HIV and Aids. The researcher conducted in-depth interviews with 24 participants who also filled in questionnaires. The aim was to explore their experiences, their challenges, and coping mechanisms. Although these volunteer caregivers shared many positive experiences, they also faced multiple challenges in the workplace, their personal lives, financial challenges as well as psychological and emotional ones. Despite these challenges, the caregivers showed only moderate levels of stress on the stress scale. Recommendations for overcoming these challenges were provided to caregivers, organisations and the Department of Health.

*Keywords:* Palliative care, volunteerism, volunteers, caregivers, stress, burnout, coping mechanisms.

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## **LIST OF ACRONYMS**

|        |  |
|--------|--|
| AIDS   | Acquired immunodeficiency syndrome         |
| ART    | Antiretroviral therapy                     |
| CSI    | Coping Strategy Indicator                  |
| HIV    | Human immunodeficiency virus               |
| NGO    | Non-Governmental Organisation              |
| PSS    | Perceived Stress Scale                     |
| UNAIDS | Joint United Nations programme on HIV/AIDS |
| WHO    | World Health Organization                  |

## **CHAPTER 1**

### **GENERAL ORIENTATION**

#### **1.1 INTRODUCTION**

Globally 35.3 million people were living with HIV by the end of 2012. An estimated 0.8% of adults aged 15-49 are living with HIV worldwide, although the burden of the epidemic continues to vary considerably between countries and regions. Sub-Saharan Africa remains most severely affected (UNAIDS, 2013). In 2010, the prevalence of HIV infections was very high in South Africa where a total number of 5.7 million people were living with HIV and Aids; this number decreased to 5,26 million by 2013 (Statistics South Africa, 2013). However the number of people dying from Aids-related causes began to decline since the major rollout of antiretroviral therapy (UNAIDS, 2013). Although there are remarkable gains to be had from antiretroviral therapy (ART) people with HIV continue to need HIV care. This includes management of opportunistic infections, medication side effects and physical symptoms. Patients also face depression, anxiety, and other psychosocial, socio-economic, and spiritual problems that can affect their quality of life and overall well-being as well as their ability to adhere to treatment and to stay in care (Green, Dix, Mwangi-Powel, Horne & Luyirika, 2010).

The high prevalence of HIV and Aids in South Africa has overstretched and overburdened the health system. Hospitals and clinics are often crowded with patients queuing to collect their medication; they need care and treatment for opportunistic infections and medication side effects for which healthcare workers can no longer provide adequate care to them. Several factors such as work overload, a shortage of patient beds, an inadequate number of trained medical, nursing and health professionals on ART's have also been highlighted. In an effort to alleviate the burden of care placed on health care workers, lay counsellors have been employed to assist with counselling and care. However, in the context of competing demands on resources, insufficient emphasis is placed on adequate training and on-going supervision and support for such personnel. High patient and workload often lead to frustration and burnout among professional health care workers (Kagee, Remien, Berkman, Hoffman, Campos & Swartz, 2011).

Coetzee, Kagee and Vermeulen (2011) mentioned that in order to avoid long queues and to reduce the length of patients' stay in hospitals through non-admission or early discharge of patients, it is imperative to use the available limited health care resources as optimally as possible. This means that it might be more practical and humane to care for patients with Aids in their own homes and communities for as long as possible. This level of home- and community-based care could serve to reintegrate Aids patients into their families where they will be able to interact with friends, neighbours and the church. Hospitals may be used as a last resort when the patient's condition has deteriorated and professional help is needed (Thabethe, 2011).

## **1.2. BACKGROUND OF THE STUDY**

In order to reduce the burden on hospitals, the South African government recognises home- and community-based care as an effective care measure in the fight against HIV and Aids. These services not only relieve the burden on hospitals and community clinics but also serve as an affordable alternative to institutional care. The World Health Organization (WHO, 2010) defined home-based care as any form of care given to people in their homes which includes physical, psychological, social and spiritual care. Care of this type may be accessed near to home, and it encourages participation by community members. Therefore, community-based care responds to the needs of people and encourages traditional community life. It was also defined by Van Dyk (2012) as the provision of comprehensive health and social services by both formal and informal caregivers in the patient's home in order to promote, restore and maintain the person's maximum level of comfort, social functioning and health.

Mashau and Davhana-Maselesele (2009) mentioned that home- and community-based care teams usually assist with various tasks such as on-going counselling and support, help with food, cooking, cleaning, wound care, hygiene, assessment of symptoms, pain and symptom management, identification of specific opportunistic infections, treatment of some of them, supervision of drug taking and monitoring of side effects. Green et al. (2010) indicated that although there have been changes since the ART rollout, patients still need home-based care. While HIV infected individuals on ART are living longer, the therapy, however, creates different needs such as therapy-related side effects that require monitoring and management in the home. Van Dyk (2010, 2011) reported that the support of people who are on ARVs could not be the responsibility of the state and the health care system alone. She mentions

that everyone should be involved, including the community, academic institutions, church organisations and employers. Hence, health professionals should offer education and counselling that is more responsive to individuals' needs. There should also be interventions that will take into consideration the reality that men are absent in many HIV affected households where the burden of care is left to women and girls. In families where men are present, they should also be oriented towards participating in caring for their sick family members.

The goal of home-and community-based care is to provide hope through appropriate and high quality care that helps family caregivers and sick family members to maintain their independence and achieve the best possible quality of life (WHO, 2010). Although many countries have developed home-based care organisations, Grant, Brown, Leng, Bettega and Murray (2011) are of the opinion that there is a greater need for palliative care in developing and developed countries as many people still die from Aids each year, in spite of the greater availability of ARVs. They mentioned that with minimal resources and huge shortages of health care workers, national health systems have focused primarily on preventative, curative and maternal health services in a number of African countries.

In many countries minimal or no resources are devoted to supportive or palliative care. However, sometimes the development of various palliative care programmes has occurred and national palliative care associations have emerged. Grant et al. (2011) reported that despite the positive change, such care is still only available to less than 5% of those who need it. Therefore, evaluations of the emerging initiatives and projects are important in order to understand how to assist people currently dying of poverty and pain due to Aids. It is crucial to introduce palliative care to those countries that do not have such an initiative (Grant et al., 2011). Palliative care treats the patient holistically while addressing their physical, psychological, emotional and social needs in a way appropriate to each person's culture and economic situation. The following section therefore focuses on the importance of palliative care as well as how it began in South Africa.

### **1.3 AN OVERVIEW OF PALLIATIVE CARE**

According to WHO (2010), palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with a terminal illness. It is a combination of active and compassionate, long-term treatment intended to comfort and



support individuals and families who live with a life threatening illness. Such care further requires a team approach that includes the patient, his or her family, community volunteers, health workers and social welfare workers. According to WHO, the purpose of palliative care is to meet the needs of all patients and their families requiring relief from symptoms as well as providing psychosocial care. This is particularly necessary for patients who are in the advanced stages of life threatening diseases (for example, Aids-related illnesses and cancer) and who have a very low chance of being cured. Because of the emotional, spiritual, social and economic consequences of HIV and Aids, palliative care services are ideal to address the needs of patients and their families (WHO, 2010).

Palliative services should be offered to patients from the time of diagnosis and should support them until death. These services may vastly improve a patient's quality of life and the ability to cope effectively (Green et al., 2010). This form of care is an important aspect of clinical management and all healthcare workers should develop the knowledge and skills required to manage patients and their families who are facing a diagnosis of a life-threatening illness.

### **1.3.1 Palliative care in South Africa**

Palliative care was initially introduced in affluent countries for cancer patients and subsequently in Africa in 1979 and to South Africa in the 1980s as well as to Kenya and Uganda in the early 1990s. The Aids epidemic significantly increased the number of people requiring palliative care and its introduction, for adults and children in South Africa living with HIV, was regarded as a major contribution (Green et al., 2010). The first such care services for people living with HIV and Aids in South Africa were started by hospices that have been established along the lines of the United Kingdom hospice model following WHO's definition of palliative care.

Meiring (2012) indicated that in the early days of the epidemic, before the wide scale rollout of ART, palliative care and home-based care programmes were established to address the needs of the dying patients and their families. Kang'ethe (2010a) defined palliative care as care that is carried out not to heal but to relieve pain, distress, psychological loss, feeling of worthlessness and anxiety. This gives hope, dignity, self-esteem, happiness and cultivates the feeling in the sick person that all will be well. The range of services provided and the availability of caregivers differ by country and region. Meiring (2012) also highlighted the need in South Africa for the care and support of people living with HIV and Aids from the

time of diagnosis throughout the course of HIV-related illness, regardless of the ability to access ART. She mentioned that palliative care is an essential component of HIV care which focuses on holistic assessment and the care carried out by caregivers.

Van Dyk (2012) defined a caregiver as a person who provides assistance to another person in need and also helps with identifying, supervising, preventing and treating an illness. She also identifies two types of caregivers providing clinical care and supportive services to people with Aids, namely the formal and informal caregiver. Formal caregivers include nurses, doctors and social workers who are trained and compensated for their caregiving activities as well as trained volunteers and spiritual counsellors. Informal caregivers include relatives, spouses, or partners and friends who provide in-home care on an unpaid basis. However, Uren and Graham (2013) also highlighted that formal caregiving involves providing care on an occupational basis and is considered something requiring acquired and learned skills whereas informal caregiving involves a family member who has no training in caregiving. The relief of suffering is of vital importance and every patient with an active progressive, complex illness has the right to palliative care. Hence, doctors and nurses have the responsibility to use the principles of such care in the care of patients with life-threatening diseases.

Dix, Green and Horne (2012) emphasised that although there have been significant gains in care and treatment of people living with HIV, in the post-ART era, patients still experience difficulties with pain and opportunistic infections as well as depression and other mental health problems. These physical and psychological problems affect adherence to treatment and the quality of life of patients as well as their families. Thus, the formation of the integration team is important, as it will help to achieve goals. Dix et al. (2012) emphasised the need for palliative care teams to work together to achieve their goals; the impact is limited when teams work individually and separately in advocating the future development of palliative care within various regions. Palliative care further requires a team approach that includes the patient, his or her family, health workers, social welfare workers and community volunteers. The issues of volunteerism and volunteer caregivers are discussed below.

#### **1.4 AN OVERVIEW OF VOLUNTEERISM**

Naidu, Sliep and Dageid (2012, p.114)) defined volunteerism as comprising acts that are done on the basis of free choice or one's own accord. They pointed out that volunteerism has

increased dramatically in the context of the HIV pandemic in Africa but indicated that governments on the continent are ill prepared and poorly resourced for the magnitude of care and support that is required. Therefore, individuals and communities have responded by volunteering care and support in areas of need, such as home-based care.

Volunteerism has been central to South African society for many years and many organisations depend on volunteers for their sustained existence. It is an activity that is considered so important in all societies that the United Nations declared 2001 the year of volunteers. South Africa followed when the President at the time, Mr Thabo Mbeki, declared 2003 the year of volunteers in South Africa. He emphasised that volunteerism is an effective mechanism through which our communities and government may work together to create a better and caring place for all of us. This was supported by President Zuma who strongly reaffirmed that individuals should volunteer to help in HIV education, testing and prevention programmes in order to reduce new infections (UNAIDS, 2010).

According to Angermann and Sitterman (2010) volunteering involves committing time and energy to provide a service that benefits someone, society or the community without expecting financial or material rewards. They further highlighted that whether formal or informal, volunteering may be described as an opportunity to do something positive and rewarding, whereby people invest in each other's well-being and support without seeking financial gain. This process of giving and sharing accords a person the experience of feeling valued and appreciated. It is also a platform for community development and social cohesion, which generates networks of friendship and support.

Volunteers are selected, trained and to a certain extent supervised; however, their own needs for caring and support are often overlooked. Given the importance of the work that volunteer caregivers perform, it seems surprising that minimal attention is given to their efforts and their personal experiences of the burdens of HIV and Aids care, in the literature (Akintola, 2010a).

#### **1.4.1 Definition of a volunteer**

The United Nations offers a broad definition of the term "volunteer" which refers to the contributions that individuals make in a non-profit, non-wage and non-career capacity for the well-being of their neighbours and society. Glenton, Scheel, Pradhan, Lewin, Hodgins and

Shrestha (2010) agreed that a volunteer is a professional or non-professional person who is willing to offer his or her time and who is strongly motivated to donate energy and skills for the accomplishment of tasks that he or she believes in. These authors further described a volunteer as a person who is willing to provide a service or performs a specific task through some kind of formal structure but receives no remuneration and does it out of his or her own free will and earns moral credit in the course of the process of service (Glenton et al., 2010). Volunteer work requires a caring spirit since no compensation or remuneration is involved, but in some organisations volunteers receive so-called stipends when funds are available.

In a multi-cultural context, such as in South Africa, it is important to consider different population groups when recruiting volunteers as they function within diverse sets of beliefs, norms and attitudes towards volunteerism. People with diverse cultural backgrounds are likely to volunteer in organisations supported by their behavioural and social networks (Akintola, 2010a). Naidu et al. (2012) indicated that gender and cultural identity also influence beliefs and people's involvement in specific organisations. They also recommended that organisations should screen applicants with the intended tasks in mind while considering factors such as safety, skills and commitment because the safety of those who receive a service must be taken into account. They further mentioned that volunteers may play important roles in complex jobs, but not without the appropriate skills, hence the importance of training them. Thabethe (2011) describes training as the process of helping people become more knowledgeable and effective in the areas that they serve.

Akintola (2010a) points out that volunteers who offer their services to non-government organisations are mostly unemployed and often impoverished. They volunteer as a means of participating in meaningful activities that enhance their acquired skills that may be useful in a future career or until they are able to obtain formal employment. When an employment opportunity arises, they relinquish volunteering, leaving the organisation with the dilemma of training new people to replace them. He further mentioned that the structure of community- and home-based care for people living with HIV and Aids would collapse without the support of volunteers. Therefore, it is important that after acquiring volunteers, organisations must seek to retain them by supporting and motivating them. Angermann and Sitterman (2010) suggest that organisations must not only understand what motivates volunteers, but also what keeps them in an organisation. Akintola (2010a) goes on to discuss the fact that volunteers' duration of commitment is a planned behaviour and their retention and commitment are

determined by the degree to which they are satisfied in terms of values, motivations and expectations.

Jack, Kirton, Birakurataki and Merriman (2011, p.707) indicated that “volunteers are trained to identify problems of the chronically ill in their area and provide intervention with support from trained professionals”. Since many projects may not get off the ground without the help of volunteers, it is important to discuss the role of volunteers in palliative care. This might assist in better understanding, supporting and managing them in organisations.

#### **1.4.2 The role of volunteers in palliative care**

The role of the volunteer within the palliative care team differs according to the healthcare setting. Volunteers come from all sectors of the community and often provide a link between health-care institutions and patients. Various volunteer organisations service different human development sectors, which include faith-based, home-based, hospitals and educational organisations. Jack et al. (2011) pointed out that with the appropriate training and support, volunteers are able to provide a direct service to patients and families. Volunteers can assist with administrative tasks, lay counselling, general maintenance and housekeeping. They can also take on several other roles, such as raising HIV awareness, providing health education and generating funds, helping with rehabilitation, or even delivering some type of medical care.

Volunteers are included in hospice and palliative care with the aim of assisting health care professionals to provide the best quality of life for patients and families. Naidu and Sliep (2012) indicated that minimal consideration has been given to the fact that there are women who volunteer for the work itself in addition to their personal and family obligations, which is an act that indicates initiative and choice. There are many women in similar circumstances who do not volunteer. While volunteerism might be seen as a means of cheap labour that exploits impoverished people, especially women, it provides a method of identifying those who are willing to work and show the initiative to train and improve their skills base. Expressing volunteerism as exploitation of the poor could make it difficult to understand impoverished people's motivation to volunteer, as well as opportunities for identifying community initiated and supported development (Naidu et al., 2012). Therefore it is

important to understand the needs that individuals attempt to satisfy through volunteer work, as well as their motivations. Different aspects concerning volunteers are discussed below.

### **1.4.3 Motivation and needs of volunteers**

According to (Akintola, 2011) volunteers are often informed about the meaning of volunteering and what it takes to be a volunteer during the recruitment interviews. They are also informed that there is no remuneration for their job in order for them to make their decisions carefully. He further mentioned that volunteers work effectively with the understanding that they are contributing to the strengthening of the community. Developing awareness and personal growth are strong motivational factors, rather than financial gain. The aspect of altruism adds value to what volunteers do and their desire to be actively engaged in community issues frequently shapes their work.

Individuals differ greatly in the nature and extent of their motivation to engage in volunteer activities; Glenton et al. (2010) mention motivation as the most important factor that encourages the individual to perform a task. In their studies of community health volunteers, they reported that volunteers are primarily motivated by social respect, religious and moral duty. However, Akintola (2010b) identified two factors that motivate individuals to volunteer: internal forces and external forces. Internal forces include the need for competence, self-growth, self-esteem, coping, the need for autonomy and reciprocity while external forces include the need for social connection, a perceived community need and being rewarded in some way.

Uren and Graham (2012) are of the opinion that understanding and identifying altruistic motivational factors does not mean that each volunteer will have a positive experience or feel fulfilled and motivated by the work they are asked to perform. They reported that in the neighbourhoods where poverty is prevalent, the sources of reimbursement, either through food or meeting transportation costs, constituted a significant pull factor contributing to volunteerism. However, they mentioned that besides the altruistic advantages of volunteering, such as alleviating problems in the communities, volunteers' intrinsic motivations affect their satisfaction regarding work. There are personal developmental gains in the process, where caregivers receive friendship and self-growth. Akintola (2010b) further identified primary needs that volunteers attempt to fulfil through volunteering; the need for achievement, for affiliation, for recognition and appreciation and for power/status. Needs and

motivations may change over time as a result of not being fulfilled, causing problems. In this study, the researcher focused on formal volunteer caregivers to discover their needs, as well as the challenges they face in their work and coping mechanisms they utilise during the process.

#### **1.4.4 Challenges experienced by caregivers**

Despite the era of ART, South Africa's health system is still overstretched and overburdened by HIV and Aids. Hospitals are often unsuitable for managing patients with terminal and long-term diseases for a longer period; hence they reduce the length of hospital stay by non-admission or early discharge of patients (Akintola, 2010b). Therefore, it might be more practical to care for patients with Aids in their own homes and communities. Usually caregivers are the ones who assume responsibility for caring for the sick people in their homes and communities. Caregivers mainly consist of volunteers both formal and informal (Uren & Graham, 2012). UNAIDS, in one of the first international reports in 2000, stated that caregivers of people living with HIV and Aids are likely to experience diverse challenges due to the fact that caregivers are involved in multiple tasks, leaving them with little or no time to attend to their own needs. In some cases they provide care to other individuals besides the person living with Aids (Uren & Graham, 2012).

Kang'ethe (2010a) found that caregiving affects caregivers' mental, physical and spiritual health. He indicated that most of the caregivers experience signs of burnout, manifesting itself as insomnia, chronic fatigue, a loss of confidence and anxiety. This is because sometimes caregivers lack even the transport needed to take their patients to the referral hospital for a check-up or review. He also highlighted that in some settings caregivers report being asked for food by their patients while they themselves are hungry. Akintola (2010a) also identified the different challenges experienced by caregivers caring for people living with HIV and Aids, including emotional, physical, financial, social, behavioural and psychological challenges. He additionally found that volunteer caregivers do not receive sufficient psychosocial support to help them cope with the challenges that they face and the different types of coping mechanisms that they employ. These are briefly discussed in the next chapter.

## **1.5 PROBLEM STATEMENT AND OBJECTIVES OF THE STUDY**

### **1.5.1 Problem statement**

HIV and Aids make considerable demands on health services that cannot be met by hospitals alone. Most of the care for people living with HIV and Aids occurs in the community and is largely carried out by volunteers, who in the main have no adequate support system. Due to lack of support, they tend to suffer from stress and burnout. This means that infected people are often inadequately looked after, regardless of the best efforts of their caregivers.

Although volunteers are doing a valuable job, they are likely to suffer from burnout if they do not receive support and adopt proper coping mechanisms. Based on the concern that volunteers receive scant attention in the literature (Akintola, 2010a), this study explored the psychosocial challenges and coping mechanisms of palliative care volunteers caring for people living with HIV and Aids.

### **1.5.2 Objectives of the study**

The main objective of this study was to explore the psychosocial challenges and coping mechanisms of palliative care volunteers caring for people living with HIV and Aids. In order to address the problem identified above, the following objectives were devised:

- To explore the reasons why palliative care volunteers offer to help people with Aids.
- To explore the psychosocial challenges faced by palliative care volunteers. This will be done by:
  - Identifying how palliative care volunteers experience their caregiving role.
  - Identifying the challenges that palliative care volunteers have to face.
- To explore the coping mechanisms used by palliative care volunteers.
- To identify the needs of palliative care volunteers.
- To identify the resources available to palliative care volunteers for people living with HIV and Aids.

Finally, the results of the study were used to make recommendations for the benefit of HIV prevention organisations and other HIV and Aids projects or programmes.



## **1.6 RESEARCH DESIGN AND PARTICIPANTS**

This study used a mixed method research design which was primarily qualitative with an added descriptive component to enhance the trustworthiness of the information. Such a design is a procedure for collecting, analysing and mixing both quantitative and qualitative data at some stage of the research process within a single study, in order to understand a research problem more completely (Creswell & Plano, 2011). The rationale for mixing is that neither quantitative nor qualitative methods are sufficient by themselves to capture the trends and details of the situation, such as the psychosocial challenges and coping mechanisms employed by the said volunteer caregivers.

Therefore, when used in combination, quantitative and qualitative methods complement each other and allow for analysis that is more complete. The research participants consisted of twenty-four (24) HIV and Aids palliative care volunteer caregivers. These participants are formal volunteer caregivers as they are recruited and trained in palliative care and do receive some form of compensation for their work. However, these payments are often minimal and are regarded as stipends, rather than salaries. A small sample size was considered as it was more manageable in a study that focuses primarily on in-depth information. The volunteer caregivers work for two non-government organisations (NGOs), Umthombo Wempilo Service Centre providing home based care for people living with Aids and Pfunekani Community Organisation catering for people living with HIV and Aids as well as orphans in Soshanguve.

## **1.7 CONCLUSION**

Palliative care professionals in South Africa experience challenges in educating and informing the community and health care professions about the position of such care in the health care system. Due to the necessity for palliative care, more volunteers are needed to care for people living with Aids in their own homes and communities. Though many of the volunteers are unemployed and live in poverty, they are generally motivated by a kindness of spirit and the will to improve the lives of their patients every day.

Caregivers carry out their work with a sense of commitment and seriously seek to end the despair of patients, but in the process they often have to deal with other problems that complicate their lives and that of their families. Although physical health problems have been

identified among volunteers, their major problems seem to be stress-related, caused by the performance of their caregiving activities. In order to understand the nature and extent of their challenges, more thorough research that provides insight into the psychosocial challenges and coping mechanisms of palliative care volunteers caring for people with HIV and Aids is necessary. Gaining such insight and understanding is able to assist with supporting volunteers in the home- and community-based care organisations. Based on the literature reviewed, this study investigated the psychosocial challenges that caring for people living with HIV and Aids pose to volunteer caregivers. Therefore, this study is an attempt to expand on the few studies that already exist.

## **1.8 OUTLINE OF CHAPTERS TO FOLLOW**

### **Chapter 2**

The *second* chapter focuses on the review of the relevant literature. The chapter discusses the psychosocial challenges of caregivers in general as well as coping and the models of coping. It further considers different ways of coping employed by caregivers.

### **Chapter 3**

The *third* chapter describes the research method used for data collection. It includes details of the characteristics of the participants and issues considered to protect the ethical rights of the participant.

### **Chapter 4**

In chapter *four* the research findings of this study are presented and discussed. Attention is given to the in-depth interviews as well as the findings of the Perceived Stress Scale and the Coping Strategy Indicator.

### **Chapter 5**

In Chapter *five* the results of the study are discussed. Recommendations are made for volunteers to improve their own work lives, as well as for organisations and the Department of Health to assist and retain volunteer caregivers. The shortcomings of this study are also discussed and recommendations for future research made.

## **CHAPTER 2**

### **LITERATURE REVIEW**

#### **2.1 INTRODUCTION**

This chapter identifies previous research conducted in the area of palliative care caregivers in relation to HIV and Aids. It seeks to establish whether previous research was conducted in relation to psychosocial challenges and coping mechanisms of palliative care volunteer caregivers in field of HIV and Aids. Relying on previous research, it identifies the motivations of the said volunteer caregivers caring for people living with HIV and Aids. The chapter also seeks to explore the needs of and available resources for palliative care volunteer caregivers.

#### **2.2 LITERATURE OVERVIEW**

According to the Department of Health (2010), statistics indicated that HIV and Aids as well as other diseases are still a challenge in the country. Community-and home-based care programmes, where volunteer caregivers usually render their services, have been established. These programmes have been established in response to the HIV epidemic and currently, the rollout of antiretroviral therapy (ART). There is a great need for research on the psychosocial challenges experienced by volunteer caregivers working in the field of HIV and Aids in South Africa. However, the literature indicates that little research has been done on the psychosocial impacts on volunteer caregivers, but has concentrated more on the “official” formal caregivers, such as professional nurses, doctors, counsellors and social workers. It has also focused on the patients, while neglecting the people that care for patients in a non-remunerated capacity.

The current lack of research is particularly surprising, given the amount of work that volunteer caregivers carry out. For example, WHO (2010) indicated that such caregivers are responsible for caring for people living with HIV and Aids and that they make a significant contribution. Although caregivers do their caregiving job out of their own free will, they are likely to experience problems rendering their services. This is confirmed by Akintola (2010a) who stated that caregiving can be a deeply meaningful way to spend one’s days on earth, but

it is also not easy to be a caregiver. This is a demanding task and caregivers commonly face various challenges in their efforts to remain effective, with regard to the provision of care.

A few studies in South Africa have explored the problems associated with volunteering, such as the occupational stress experienced by caregivers and the emotional impact of HIV and Aids on health care workers, perceptions of rewards and motivations of volunteer caregivers (Akintola, 2010a; Akintola, 2010b; Akintola, 2011; Kang'ethe, 2010b; Mashau & Davhana-Maselesele, 2009). In this chapter, the psychosocial challenges and coping mechanisms of palliative care volunteers caring for people with Aids are explored through a literature review. Thereafter, two models: the transactional model of stress and coping and the Broaden and Build theory of positive emotions, are discussed in terms of informing existing knowledge and understanding of caregivers' coping processes.

### **2.3 THE PSYCHOSOCIAL CHALLENGES FACED BY HIV AND AIDS CAREGIVERS**

Several studies have been conducted to assess experiences, burnout and stigma in caregivers providing care for people living with HIV and Aids (Mashau & Davhana-Maselesele, 2009; Singh, Chaudoir, Escobar & Kalichman, 2011; Van Rooyen, Williams & Ricks, 2009); however none of these studies have focussed specifically on the challenges faced by palliative care volunteer caregivers caring for people living with HIV and Aids. According to Wringe, Cataldo, Stevenson and Fakoya (2009), caregiving is a demanding task (as mentioned above) and working with HIV-infected and Aids patients places a considerable emotional demand on the caregivers as they have to provide HIV education and emotional support to patients and their family members and adherence to drug regimens, including ART. Hence, psychologists use the term "caregiver burden" to describe the physical, emotional, financial and social problems associated with caregiving (Singh et al., 2011).

The burden can be assessed in terms of the objective or subjective impact of caregiving on caregivers. The objective burden assessment views the extent to which caregiving negatively affects resources and disturbs daily routines and social relationships. Examples of objective burdens include forced changes in household routines, missed days of work, reduced social contact, loss of income and reduced energy. Subjective burdens encompass the caregivers' perception of and response to caregiving demands. Different psychosocial challenges, as

previously described, i.e. physical, psychological and emotional, social and behavioural as well as financial and workplace related challenges, are discussed below.

### **2.3.1 Physical challenges**

Jack et al. (2011) reported that most caregivers experience some form of physical burden as a result of caregiving. These physical demands contribute to the caregiver burden because they may be required to perform multiple and sometimes conflicting roles. Akintola (2010a) mentioned that the physical burden usually stems from lifting, carrying and physically supporting patients. He identifies the physical consequences associated with caregiving as sudden and recurring head and body aches, fatigue and muscle strain from lifting and supporting the patients and doing other chores. For some of the volunteer caregivers, walking long distances in the hot sun to patients' houses is also physically stressful. In the same study conducted in a semi-rural part of South Africa, it was reported that caregivers are likely to ignore these physical impacts and delay seeking assistance while prioritising the need of their patients.

### **2.3.2 Psychological and Emotional challenges**

The literature frequently reports on the described challenges experienced by caregivers (Mashau & Davhana-Maselesele, 2009; Akintola, 2010a). Some authors conclude that caregivers are inclined to become emotionally involved with their patients to compensate for the unfair treatment, discrimination and stigma that patients have to face. In their research on the caregiver burden, Mashau and Davhana- Maselesele (2009) have found that volunteers tend to become emotionally too involved, stretch themselves too far to meet work-related demands and thus become emotionally exhausted. They also begin to internalise some of the hardships their patients are experiencing (Meiring, 2012).

Meiring (2012) reported that even with the availability of ART, caregivers are still subjected to emotional challenges when caring for patients infected with HIV and Aids. She also indicated that caring for people with HIV and Aids places considerable emotional demands on caregivers to the point of affecting their mental health. Morwe and Ramaila (2012) stated that during the 1980s there was a fear of contagion which was mainly related to the lack of knowledge about HIV and Aids. Fear is further exacerbated by caregivers who fail to maintain consistent and appropriate infection control precautions. Mashau and Davhana-

Maselesele (2009) stated that the nature of HIV infection and being unprepared for various situations moreover create a significant burden and contribute to caregivers' fear. The fear of infection is aggravated by increasing infections due to lack of resources, poor adherence to ART and rapid changes in the field of HIV and Aids care which poses a problem for volunteer caregivers as they are expected to provide much more than just physical care for patients. Expectations include providing psychosocial support such as guidance, counselling and bereavement counselling (Ebersohn, Eloff & Swanepoel-Opper, 2010).

Mashau and Davhana-Maselesele (2009) asserted that caregivers often feel powerless and hopeless when their patients are terminal. Caregivers usually have to provide care in trying conditions as there is no cure and their scope of practice is limited. This contributes to feelings of anxiety and worry about the deterioration of the physical state of their patients, which they are unable to manage. These feelings are compounded if caregivers suspect that they are also living with HIV. Akintola (2010a, p.58) asserted, "It is impossible for caregivers to distance themselves from their patients because they see their own symptoms and problems reflected in them and also observe personally how they too may become sick and die." This constant exposure to death and the fact that caregivers do not have the opportunity to grieve often results in bereavement overload.

The issues highlighted above, cause considerable stress, anxiety and discomfort for the volunteer caregivers working with HIV and Aids patients. Akintola (2010a) also pointed out that caregivers, who are already infected, may worry that no one will be around to take care of them when they become sick. The issue of confidentiality, another psychological challenge that caregivers often experience, is discussed below.

### **2.3.3 Confidentiality and disclosure**

Van Bogaert and Ogunbanjo (2009) defined confidentiality as an essential requirement for the maintenance of trust between the patients and health care workers and is based on legal and ethical safeguards. Patients expect health care workers to keep their health information confidential because such information is usually given in confidence and trust. Sowell and Phillips (2010) indicated caregivers are often called "keepers of secrets" when they try to maintain the principle of confidentiality. Fear of negative social consequences often causes caregivers to keep their patient's HIV status a secret. This was supported by Kang'ethe (2010b) who reported that caregivers sometimes have to keep their patients' status secret (in

cases where patients did not disclose their status to family members), which places the caregivers squarely between the patients and their families. This is because family members frequently ask them about the cause of a patient's illness, which they feel they must not reveal. The requirement of no disclosure even after and in the midst of a patient's death places considerable pressure on the caregiver, creating a heavy psychological burden for them.

Brown, Oladokun, Osinusi, Ochigbo, Adewole and Kanki (2011) documented in their study that volunteers did not encounter difficulties keeping secrets or confidential information about their patients. However, it was stressful for them to maintain confidentiality about their patient's HIV status as they are usually seen by families as betraying their trust when the families and children find out about the status of their loved ones. Although volunteers assured patients about the confidentiality of the information to which they had access, it was difficult, resulting in negative psychological and negative social effects for themselves.

The keeping of secrets also affects the ability of the caregiver to establish and maintain good relationships, and drains caregivers' emotional energy, leads to isolation and causes inner conflict. All the ethical dilemmas mentioned above, together with a lack of appropriate community resources and facilities, can create a sense of failure among caregivers in the Aids arena. Yeap, Hamilton, Charalambous, Dwadwa, Churchyard, Geissler and Grant (2010) and Campbell and Cornish (2012) pointed out that disclosing one's HIV status is one of the essential elements in behaviour modification. It can also increase the patient's access to HIV treatment and management programmes and may assist in decreasing the levels of community stigma. Caregivers also experience stress when they fail to communicate with their patients because they do not understand each other's language; they therefore find it difficult to communicate with their patients about issues like disclosure.

#### **2.3.4 Social and behavioural challenges**

Majumdar and Mazaleni (2010) reported that caregiving is time consuming, and as a result, caregivers often do not have adequate time and energy to care for themselves. This may include using their own time to assist their patients, consequently neglecting their own social lives. They further mentioned that caregivers may not have time for social activities such as religious gatherings and social meetings. The impact of the disease on the functioning of the family often increases the workload of volunteers. The workload is also increased by

additional dependants, such as children orphaned by the epidemic and older relatives who require care, who are frequently taken into the family.

Caregivers often do not conduct a social life as they are obliged to assist in households if the patient does not have other family members to assist. Furthermore, it is painful for caregivers to observe situations where children are forced to stop attending school to take care of their sick parents. Caregivers therefore often walk the extra mile and put in additional hours to assist households so as to lessen the burden on children. If there are no other family members to take care of the patient, volunteers are forced to spend more time with the household than expected and the amount of time and energy to carry out the work also increases dramatically (Kang'ethe, 2010a).

In addition to the above findings, Bemelmans, Van den Akker, Pasulani, Tayub, Herman, Mwagomba, Jalasi, Chiomba, Ford, & Phillips (2011) contended that caregivers often neglect their own self-care with regard to nutrition, exercise, socialising and sleep because of the multiple tasks that they are obliged to perform every day. They might develop behaviour that has a negative impact on their health such as smoking, not exercising and overeating, leading to weight gain and other lifestyle diseases. Majumdar and Mazaleni (2010) added that caregivers who are overworked and stressed commonly isolate themselves from others and become secretive and defensive and even become uncertain about how people will identify them, receive them and treat them due to the stigma by association and discrimination that they experience in their communities. These latter two issues are addressed in the following section.

### **2.3.5 Stigma and discrimination**

The literature reports that discrimination and stigma towards caregivers are factors that may increase stress. Singh et al. (2011) define stigma as a dynamic process of devaluation that significantly dishonours an individual in the eyes of others. The issue of stigma has been identified as a barrier to health care, social support and disclosure (Haber, Roby & High-George, 2011). Caregivers are often afraid to disclose information that links them to the epidemic and will often keep the fact that they care for Aids patients a secret from family and friends. Singh et al. (2011, p.841) wrote that stigma legitimises the decision to withdraw sympathy and assistance. Stigma has an imprisoning effect, which keeps caregivers away,



who have already reduced their social contact with others. Stigma about Aids often affects whether and how people engage with the health system and with the caregivers.

According to Singh et al. (2011) discrimination is the prejudicial or distinguishing treatment of an individual in a way that is worse than the way people are usually treated. Kang'ethe (2010b) pointed out that the potential impact of stigma and discrimination has been an ongoing concern to those involved in the fight against the Aids epidemic. Stigma and discrimination exert a negative impact on those who are infected and affected. They also have a number of implications such as limiting access to treatment, causing the epidemic to be invisible, because individuals who have contracted HIV are forced into hiding instead of disclosing their status. He also asserts that fear of discrimination limits the possibility of disclosure, even to those who are important sources of support, such as volunteer caregivers. This creates a huge burden on them, affecting their psychological well-being.

Campbell and Cornish (2012) reported that HIV-related stigma has unique qualities in addition to the other stigmas such as race, gender, homosexuality and promiscuity; hence there is discomfort among some caregivers when dealing with Aids and sexuality. For some caregivers, caring for homosexual Aids patients may be a caregiver's first experience of working with individuals with this sexual orientation. This may be a potential source of stress and uneasiness for them. Homophobic attitudes can interfere with the caregiver's provision of quality care to the person with HIV and Aids.

### **2.3.6 Financial challenges**

Volunteer caregivers also often experience a financial burden. A study by Kang'ethe (2010a) reports that volunteer caregivers suffer economic stress because many of them are unemployed and live in similar socio-economic conditions as those for whom they are caring. He further mentions that, in many instances, caregivers need as much support as the patients and the affected households they are assisting. Morwe and Ramaila (2012) asserted that the effect of poverty on patients discourages HIV and Aids volunteer caregivers. In their study of the situation of caregivers in Thohoyandou in the Limpopo province, they established that many volunteer caregivers express feelings of helplessness because their patients are so poor. For example, they find it very difficult to promote the importance of nutritional support in poor areas where people do not have enough food to eat. They also highlighted that

caregivers report many instances of giving their own lunches or money away to alleviate hunger among patients, as patients cannot take their ARV's without food.

Grant et al. (2011) pointed out that the reduction in the patient's household income, mainly due to the illness of the breadwinner, is another challenge for volunteer caregivers. When the breadwinner is very ill there is the difficulty of an increase in the cost of daily living, especially with the need to purchase medicine, paying for medically-related expenses, transporting the patient to the clinic or hospital and the need to purchase special food for the sick person. In addition, caregivers are obliged, in certain instances, to arrange with other household members to sell off some of the patient's assets to meet those needs. In his study, Kang'ethe (2010b) also indicated that in homes where volunteers are serving as the primary caregivers, they are sometimes under pressure to provide food and money for transport to health facilities. While worrying about their own financial situation and that of their patients, they become even more stressed. Volunteer caregivers often provide services beyond the call of duty and this places an exceptionally heavy strain on them.

### **2.3.7 Workplace-related challenges**

Coetzee et al. (2011) indicated that the environment in which caregivers doing home- and community-based care in South Africa demand more of them than any previous period did. The demand is immense as there has been an increase in non-admission and or in early discharge of patients to be taken care of in their homes. Caregivers must often meet many needs with very limited resources and a lack of control over the environment. Some caregivers also face diminished choices about their job and lack of control in that they are forced to work many hours and have to submit to working arrangements with which they do not agree. While caregivers are required to fulfil conflicting role requirements, they are likely to experience job stress as role conflicts create expectations that may be hard to satisfy. For example some families demand that volunteers should do all the house chores and other caring activities for them because "they are getting paid for it". Other patient expectations relate to the scope of practice of the volunteers as they are not trained to administer drugs or injections, resulting in patients being disappointed when they are told that the volunteer cannot administer drugs but only assist with basic nursing care (Kang'ethe, 2010a).

Darling, Olmstead and Tiggelman (2010) concur with the above view and emphasise that it is the relentless complications involved with working in the Aids field that lead to impaired

care. Caregivers experience many difficulties in their work environment, resulting in high job stress. These are a lack of time, conflicting demands from patients and families as well as considerable uncertainty about the disease and its progression. Uncertainty in the workplace includes being underprepared for various situations, including death. Uncertainty also occurs when caregivers feel they can no longer make a difference and when they see death as a personal failure. They also identify certain organisational factors, especially a lack of emotional and practical support, lack of supervision and mentoring, interpersonal conflict, work overload as well as the lack of infrastructure (Darling et al., 2010).

The unrealistic expectations of what can be accomplished by caregivers, as well as a lack of decision-making autonomy, work overload, communication problems between caregivers and organisation staff, role conflicts, inadequate medical resources and referral arrangements are some of the stressors that caregivers often experience as reported by Kang'ethe (2010a). The challenges discussed above may lead to stress and if they are not taken care of, they lead to burnout amongst caregivers. For this reason it is important to understand the meaning of the terms "stress" and "burnout" as they are always mentioned in the research on caregivers.

## **2.4 STRESS AND BURNOUT**

Akintola, Hlengwa and Dageid (2013) in their study about perceived stress and burnout among volunteer caregivers working in Aids care indicated that caregivers usually experience stress. They further mentioned that stress affects physical, mental, personal and social functioning. Akintola et al. (2013) defined stress as the process that occurs when people find themselves unable to deal with the stressors facing them. It is a state of tension felt in the presence of a task that is perceived as presenting a challenge to one's safety or self-esteem. Stress occurs when there is a perceived discrepancy between environmental demands and one's ability to meet those demands. Stress has both psychological and physiological causes and effects.

Kang'ethe (2010a) indicated that human beings are naturally endowed with coping capabilities and resources, but that stress usually results when these capacities are overburdened. He mentioned that when our body experiences stress, there is a rush of adrenalin, heightened muscle tension, a faster heart rate and raised blood pressure. If our body experiences stress on a daily basis, the body will soon suffer and distress will be experienced. In effect, managed stress can contribute to personal growth and development;

however, excessive stress is generally harmful. How we react to stress depends on whether we see ourselves to be in control of the situation or overwhelmed by it, which leads to burnout.

Lee, Li, Jiraphongsa and Rotheram-Bonus (2010) described the term “burnout” as not an event but a process in which everyday stresses and anxieties that are not addressed gradually undermine the caregivers’ mental and physical health, so that eventually caregiving and personal relationships suffer. According to Kang’ethe (2010a, p.548) burnout is a “syndrome of emotional exhaustion, depersonalisation and reduced personal accomplishment that can occur among individuals who work with sick people”. He mentioned that burnout is a state of emotional and physical exhaustion characterised by lack of concern for the job, low trust of others, loss of caring and self-depreciation. Cox, Pakenham and Cole (2010) pointed out that caregivers sometimes suffer from emotional exhaustion, which occurs when a person becomes too emotionally involved and stretches himself or herself too far to meet work related demands. They further explained depersonalisation as characterised by negative, detached and even inhumane attitudes and behaviours towards recipients of services. In some instances, caregivers may have experienced low personal accomplishment as a result of stress.

Reduced personal accomplishment involves a negative perception of one’s work that may lead to feelings of inadequacy and failure and that leads to stress and burnout. However in their study about testing a demands-resources model with HIV/Aids volunteers, the above authors have found that emotional exhaustion is of concern for these volunteers with regards to possible mental health outcomes, but that depersonalisation has not occurred. Rather, a sense of accomplishment was found to be most potent as a mechanism for linking between demand and resources and intrinsic satisfaction (Cox et al., 2010). Hence, caregivers must alter their responsibilities and social activities in order to adapt to the caregiving role. It is therefore important to understand the different methods that caregivers adopt to cope with their psychosocial challenges. The discussion below will now attempt to focus on the caregivers’ coping mechanisms.

## **2.5 COPING**

Kang’ethe (2010a) indicated that under normal and natural circumstances, coping constitutes the actions taken by individuals and animals when faced with stressful events in order to

lessen the threat to them. HIV and Aids caregiving takes place in a stressful environment where there is little control over many of the stressors that affect caregivers' wellbeing. Consequently, caregivers require certain skills that will enable them to take control of their lives and care for themselves. Accordingly, individuals need to understand their stress cycles and how to control their responses to stress. Therefore acknowledgement of current problems experienced by caregivers in the HIV and Aids field, while accepting the responsibility for managing their stress levels, will promote coping in stressful environments.

### **2.5.1 Definition of coping**

Lazarus (1991, p.112) defines coping as a "person's continuously changing cognitive and behavioural efforts used to manage specific external or internal demands that are considered as being beyond the resources of a person". For an individual to continue functioning in an adaptive way, he/she must learn to cope with stress. He further describes coping strategies as purposeful attempts or efforts to solve a problem without the requirements of reaching an immediate agreement.

### **2.5.2 Coping mechanisms**

Thoits (2011) defined coping mechanisms as the methods or strategies people employ to deal with the minor or major stress, trauma, pain and natural changes that they experience in life. Some of these strategies are unconscious, others are skills consciously mastered in order to reduce stress, while yet others are learned behavioural patterns used to cope with the situation. People are not always able to cope with the difficulties that they face, as not all coping mechanisms are equally effective.

He further indicated that there are both negative coping mechanisms and positive ones. Therefore, many people use coping mechanisms that benefit them in a positive way while others choose mechanisms that can actually increase stress due to a failure to explore and assess the main causes of their stress. Researchers Lazarus and Folkman (1984) identified two coping responses: problem-focussed and emotional-focussed coping. Problem-focussed coping is known as confrontive coping. This strategy is used by the individual to identify causative factors for an occurrence, and then devising means and ways of dealing with these in an effective manner. This form of coping is goal-directed and the focus is on defining the problem and generating alternative solutions.

Emotion-focussed coping is the avoidance of a problem which may be used to maintain hope and optimism, but it may also be used to deny both facts and the implications of the truth. It is generally used when individuals believe they are unable to change a stressful situation (Lazarus & Folkman, 1984). Akintola et al. (2013) has found that, initially, volunteer caregivers tend to use emotion-focussed coping strategies such as denial, anger and impatience, which causes considerable stress for them as it does not solve their problem. When they decided to adjust and consider the situation as a challenge that needs them to develop other coping strategies. Hence, they employ a problem-focussed coping strategy that helps them to become competent. Before discussing the different ways in which caregivers cope with their psychosocial challenges, two models for consideration are: the Transactional Model of stress and coping and the Broaden and Build theory of positive emotions, which will be discussed in order to understand how volunteer caregivers cope with their challenges.

## **2.6 MODELS OF COPING**

There are many coping models used by theorists that may be examined in order to evaluate the process of coping with stress, providing insight into the ways in which individuals cope with their everyday challenges. The transactional model of stress and coping and the Broaden and Build theory of positive emotions are discussed below.

### **2.6.1 The Transactional Model of stress and coping**

The Transactional Model of stress and coping theory, developed by Lazarus and Folkman (1984), constitutes the broad theoretical framework for this study. In order to understand the coping strategies that Aids caregivers use in their daily work, one should regard the caregiving job as a transaction between the caregiver and the patient. According to the theory of the Transactional Model of stress and coping, the patient and the caregiver engage with each other on a transactional level of give-and-take, which should balance itself out at the end of the caregiving process.

The theory additionally investigates how the volunteer caregivers react to a problem and what coping strategies they need to develop in order to deal with the situation. Psychological stress is viewed as a particular relationship between the person and the environment that is considered by the person as going beyond his or her control and disturbing his or her well-being (Uren & Graham, 2013). Such judgments are determined by perceiving environmental

demands and personal resources, which can change over time due to coping effectiveness or improvement in personal abilities. Lazarus and Folkman (1984) demonstrate that cognitive appraisal and coping, as the actions taken by individuals when faced with stressful events in order to lessen the threat to them, are important mediators of stressful person-environment transactions. Cognitive appraisal is the personal interpretation of a situation; it is the manner in which an individual views a situation, which in turn may be subdivided into two components namely, primary and secondary appraisal.

Lazarus and Folkman (1984, p.186) explain that primary appraisal refers to “a person’s judgment about the significance of an event as stressful” or threatening. It entails the individual evaluating whether the situation may bring harm or not. At this stage, the volunteer caregivers assess their capabilities, social support and other resources to face the challenges and to re-establish the balance between themselves and the environment. Therefore, when faced with the psychosocial challenges associated with caregiving work, volunteer caregivers evaluate the potential impact on their lives. During this process, volunteer caregivers judge the significance of the event as being stressful, positive, manageable or challenging. If it is recognised that the stressors do not entail any danger, the coping process will be stopped. In the event that danger or a threat is perceived, the individual then moves into the process of secondary appraisal.

Secondary appraisal is an assessment of people’s coping resources and options that are available for coping with the threat, or perceived danger, as well as the constraints and consequences of using those resources. A secondary appraisal helps the volunteer caregivers in terms of what may be done about the situation and what coping mechanisms are available to alter the situation from a stressful experience to one with a positive outcome. Lazarus and Folkman (1984) also found that the stressors often go beyond the demands made by the internal and external environments of caregiving. A stressful experience is perceived as a complex and dynamic system of transactions between the volunteer caregiver and the environment. Volunteer caregivers mediate these transactions because they assess the stressors according to their access to the psychological and social resources at their disposal, based on different aspects, such as adequate training and continuous support.

Coping processes are initiated in response to the assessed demands of the specific situation, which include actions, a change in thinking, redefining the situation, any other appropriate subjective solution or anything else considered appropriate after the individual’s primary and

secondary appraisal. Uren and Graham (2013) recognised that emotion-focussed coping is used in situations where nothing can be done and in situations that have to be accepted to regulate distress. Positive emotions such as happiness, relief or pride are also experienced only when the situation is resolved effectively. Positive emotions have received little attention in empirical research, whereas negative emotion is the centre of focus due to its psychological impact and the need to find solutions and remedies for those problems. The Broaden and Build theory of positive emotions discussed below will highlight the importance of positive emotions used by volunteer caregivers to cope with stressors and improve their well-being.

### **2.6.2 The Broaden and Build theory of positive emotions**

Johnson, Waugh and Fredrickson (2010) indicated that the broaden hypothesis, part of Frederickson's Broaden and Build theory, proposes that positive emotions lead to broadened cognitive states. They reported that the said theory describes a form and function of a group of positive emotions such as joy, interest, contentment and love. Positive emotions can facilitate the development of skills, networks, resources and capabilities, which, in turn, promote well-being and fulfilment. According to Cohn, Fredrickson, Brown, Mikels & Conway (2009) the theory also suggests that positive emotions broaden one's awareness and also develop changes that can function to build lasting resources. They further emphasise the point that unlike negative emotions which narrow attention, cognition and physiology towards coping with an immediate threat or problem, "positive emotions produce new, broad-ranging thoughts and actions that are usually not critical to one's immediate safety, well-being or survival" (Cohn et al., 2009, p.61).

The personal resources then function as reserves that may be later drawn on by caregivers to improve the chances of successful coping and survival. The broadened mind set arising from these positive emotions is contrasted with negative emotions, which prompt narrow, immediate survival-oriented behaviours. For example, Cohn et al. (2009, p.66) indicate that "the negative emotion of anxiety leads to the specific fight or flight response for immediate survival whereas fear leads to escape or avoidance of the immediate situation". They further mention that negative emotions experienced during life-threatening situations narrow an individual's thoughts and actions, whereas positive emotions present new possibilities, providing the individual with a wider range of thoughts and actions from which to choose.



Garland, Fredrickson, Kring, Johnson, Meyer and Penn (2010) reported in their study that caregivers who experience positive emotions exhibit a high level of creativity and perceptual focus. These caregivers who use positive emotions can develop a long term resource such as psychological resilience, flourishing both in the present and in the future. Positive emotions can counteract caregivers' lingering negative emotions because they put the negative emotions into a broader perspective. If caregivers can cultivate these positive emotions, they can use them to help cope with the negative emotions that they experience during their work. Garland et al. (2010) explain that because caregivers usually experience stress, positive emotions can help them to deal with what is occurring and move forward and away from the negative situation. The broadening effects of positive emotions may also increase the probability of finding good in future events. It has been reported that highly resilient caregivers are those who experience more positive emotions than negative ones even in the face of stress.

Cohn et al. (2009, p.362) identify "ego resilience as a fairly stable personality trait that reflects an individual's ability to adapt to changing environments." Furthermore, they examine the relationship between positive emotions and a change in ego resilience in their study. They find that, when faced with a stressor, caregivers with high ego resilience experience more positive emotions than do their less resilient peers. They further state that, although positive emotions and ego resilience are interrelated in multiple ways, ego resilience provides benefits in negative as well as positive situations.

Akintola (2010b) mentioned that although many caregivers report suffering from stress and burnout, there are also those who experience joy and fulfilment. For example, there are volunteer caregivers who continue with volunteer work because it is socially fulfilling to them. Volunteers also reported that volunteering gives them an opportunity to meet others and therefore develop friendships; knowing that they have added value in someone's life fills them with glow of internal satisfaction and joy (Akintola, 2010b). Sauter (2010) indicated that studies usually distinguish between negative emotions such as disgust, sadness, anger and fear: in contrast, most research uses only one category of positive effect, "happiness", which is assumed to encompass all positive emotional states. Therefore, the Broaden and Build theory of positive emotions emphasises the view that individuals who experience positive emotions such as enjoyment, happiness, joy and interest, broaden their awareness and encourage different and exploratory thoughts and actions.

Garland et al. (2010) identified meaning-focussed coping as one of the strategies that are used by caregivers to cope with their challenges. They defined this form of coping as a strategy in which a person draws on his or her beliefs, values and existential goals to motivate and sustain coping and well-being during difficult times. They further reported that positive emotions have been identified as important components in the link between religion and health. They added that the aspect that makes religion beneficial to people is the fact that they are built on the belief of greater meaning in life. People are able to find meaning in anything, for example through volunteering. They understand and embrace the fact that dealing with others out of genuine concern and love bears positive results (Garland et al., 2010).

Jiminez, Niles and Park (2010) in their study have reported that higher levels of dispositional mindfulness were associated with higher levels of positive emotions, mood regulations expectancies and self-acceptance. This indicates that some caregivers might understand and use the benefits of positive emotions to their own advantage. Caregivers with high resiliency are said to “bounce back” from stressful experiences quickly and efficiently. The association between resilience and positive emotions is supported by the network of correlates of resilience discovered across a range of self-report, observational and longitudinal studies. This converging evidence suggests that resilient volunteer caregivers have optimistic, energetic approaches to life. They are curious and open to new experiences and are characterised by high positive emotionality (Johnson et al., 2010). They further added that resilient caregivers do not cultivate positive emotions to themselves only; they are also skilled in eliciting positive emotions in others. For example, they are caregivers early in life and become companions later, and this creates a supportive social context that facilitates coping.

## **2.7 DIFFERENT WAYS OF COPING EMPLOYED BY CAREGIVERS**

The literature on caregiving describes a wide range of strategies on preventing and managing stress and burnout. According to Andersen (2012), most of these strategies focus on ways of managing the caregiving situation, rather than on eliminating or reducing stressors in the caregiving environment. There are many ways to cope, varying from avoiding stress or denial of stress at one extreme to seeking and confronting the source of stress. According to Magill (1976) coping attempts either to reduce the demand, to reduce its effects, or to help one change the way one thinks about the demand. It also attempts to eliminate or moderate the initial source of the stress reaction (stimulus-directed coping), reduce the magnitude of the

stress response (response-directed coping), or change the way the stressor is perceived (cognitive coping). For individuals such as caregivers in the HIV and Aids field, both the internal factors (such as knowledge) and external (such as money or friends) are necessary to help one cope with a stressful event. Caregivers are advised to re-evaluate caregiving demands and resources, clarify values and priorities and adopt coping strategies that match the nature of the stressors (Andersen, 2012).

Kang'ethe (2010a) reported that caregivers who use problem-focussed strategies to cope with stressful situations are less likely to experience burnout because they gather information, plan and take direct action whereas those who use emotion-focussed strategies try to escape or avoid the problem. Researchers have identified different types of coping mechanisms such as building a support network, establishing caregiver support groups, changing caregiving patterns, providing respite care, education and counselling, striving for good health, adopting relaxation techniques and the memory box technique, all of which are discussed in detail below.

### **2.7.1 Build a support network and caregiver support groups**

Empirical studies suggest that caregivers with more social support are less likely to experience the negative outcomes of caregiving. Singh et al. (2011, p.843) defines social support as “helpful functions performed by significant others such as family members, friends, co-workers and neighbours and thereby enhancing the individual’s physical and psychological well-being.” Social support comprises the helpful functions or supportive resources that are provided for caregivers to enhance their physical and psychological well-being. Good social support reduces feelings of social isolation and offers humour, recognition, and encouragement as well as a valuable source of new information.

Kang'ethe (2010a) contended that support groups help caregivers to come together, share feelings, experiences and also to learn from one another. The purpose of a support group is not to change participants’ behaviour as in group therapy, but rather to improve their decision-making capacity and coping skills. He also suggests that support groups can significantly reduce caregiver stress. However, these groups cannot be a substitute for professional counselling or therapy when these services are needed. Support groups provide a room for emotions that cannot be expressed at home and also provide the opportunity for caregivers to become better informed about HIV and Aids, new treatments and community

resources. Akintola (2010b) indicates that in some communities, caregiver support groups may not be easily accessible because of a variety of common factors such as a lack of money for transport, stigmatisation and isolation of the caregiver. Hence, telephone support groups may be an option for caregivers who wish to maintain anonymity or who cannot attend support group meetings.

### **2.7.2 Change caregiving patterns and respite care**

Caregivers sometimes become so involved in their work that they confuse their responsibilities. Such caregivers are likely to burn out quickly. Kohli, Purohit, Karve, Bhalerao, Karvande, Rangan, Reddy, Paranjape and Sahay (2012) assert that this situation can be avoided by helping caregivers to establish realistic goals based on an honest assessment of what they can and cannot do. Caregiving can be changed by breaking down tasks into small acts and learning how to adjust to the pace of caregiving. The burden of caregiving may also be relieved by asking others to help with caregiving tasks, which can be done once goals are established (Kohli et al., 2012).

Kang'ethe (2010a) indicated that the constant demands of the job may cause caregivers to neglect friends, interests and activities that once gave them pleasure. Health professionals should encourage caregivers to take regular breaks and to keep up with their interests and hobbies as best they can. For some caregivers, outside employment may provide relief from everyday tension and respite care can be another way to assist caregivers to cope. Salin, Kaunonen and Astedt-Kurki (2009) explained that respite care provides short-term, temporary, non-medical care to people with terminal illnesses in order for the caregivers to get some rest, take a holiday or attend to personal tasks.

There are different respite care programmes. Some send a replacement caregiver to the patient's home, while others require the patient to come to the respite care facility. Salin et al. (2009) argue that studies of the impact of respite care have documented significant improvements in caregivers' emotional well-being and perceived ability to cope. However, these effects may be short lived without repeated use. Services are provided for a varying length of time but this depends on the primary caregiver's needs and available resources. It is important for the caregiver to make use of this type of service as it is provided by a variety of organisations, including adult day care centres, hospitals, in-home care services, nursing homes, schools and faith communities.

### **2.7.3 Educating and counselling caregivers**

Jack et al. (2011) report that many of the stressors contributing to burnout are caused by the “caregivers’ lack of useful information or misinformation about the patient’s condition, type of tasks performed, medication, equipment and referrals”; hence health professionals should offer them appropriate education. As the caregivers’ levels of education and knowledge differ, the health care professionals should assess the needs, characteristics and resilience of caregivers in order to set up an educational programme that will accommodate their individual needs such as disease processes, coping skills, problem-solving skills and support.

According to Yeap et al. (2010) caregivers should receive on-going education because there are often changes in terms of treatments and treatment procedures, the patient’s condition and the standard of care. They need to be taught that they cannot stop the progression of the disease and should be assisted to set realistic goals for themselves. Education can increase caregivers’ knowledge about the disease. Disease management improves caregivers’ physical and mental health, well-being and decreases caregiver stress and delays the institutionalisation of the patient.

Kang’ethe (2010a) contended that the information gained from a systematic assessment of caregivers’ burdens places health professionals in a stronger position to help the caregivers cope with stressors. It was therefore indicated that during each medical assignment caregivers should be given an opportunity to discuss what is happening in their lives as well as a chance to express their feelings. Caregivers should also be helped to identify and build on certain areas of their lives that contribute to physical, psychological and social wellbeing. Caregivers experiencing guilt, hopelessness or spiritual distress may need to be referred for religious or spiritual counselling while those caregivers suffering from psychological problems should be referred to mental health professionals for assessment and counselling.

Health professionals sometimes overlook the importance of extending counselling into the bereavement period. If caregivers providing care had a close relationship with the patients, grief may extend for two or more years after death. Bereavement counselling can therefore help them “mourn appropriately; cope with the changes resulting from their loss and pain for the future” (Yeap et al., 2010, p.1105).

#### **2.7.4 Strive for good health and adopt relaxation techniques**

According to Weaver and Jackson (2010), health means being well or healthy in one's body, mind and spirit, and living in a healthy family, community and environment. A healthy lifestyle plays an important role in burnout prevention. Caregivers should eat three balanced meals every day, engage in regular physical activity and sleep properly in order to increase their capacity to manage stress. To promote fitness and build muscular strength, caregivers must engage in an exercise programme in order to increase energy and provide a needed outlet for unexpressed emotions. Knight and Sayegh (2009) reported that maintaining a regular exercise regimen along with a spiritual focus can be an effective coping strategy. They also mention that some caregivers react to stress by engaging in unhealthy behaviours such as smoking, drinking and drug misuse. Such caregivers should be informed of the harmful effects of these behaviours and be encouraged to rather participate in counselling and treatment programmes in order to keep themselves healthy (Bemelmans et al., 2011).

According to Kumar and Jim (2010), caregivers should use relaxation techniques to manage stress and prevent burnout. These techniques should fit in with the individual caregiver's interests, time and resources. Some caregivers may wish to learn yoga and tai chi, while others may prefer to take a walk, listen to music or soak in a warm bath. There are some additional relaxation techniques recommended by caregivers. Such techniques include meditation, deep breathing exercises, massage therapy, gardening, exercising, reading and socialising with friends.

#### **2.7.5 Memory box technique as a coping strategy**

The memory box technique was introduced by Ebersohn, Eloff and Swanepoel-Opper in 2010 as one of the techniques that can be used by volunteers to cope with the psychosocial challenges they experience in their field of work. A memory box is created to store letters, photographs, tapes and any object relating to anything that is significant to the "box maker". They mentioned that the purpose of the memory box is to improve resilience in volunteer caregivers and to facilitate the process of grief and bereavement as well as to help them to cope in difficult times. Ebersohn et al. (2010, p.80) view the making of a memory box from a "positive psychology view as a way of bringing out awareness of positive emotions as well as positive traits whereas a narrative therapy view allows people to create alternative stories rather than remaining in stories of illness and death." The making of a memory box helps

people to build identity and strengthen emotional capacity, enabling them to understand the past and not fear the future.

In effect, memory box making lightens volunteer caregivers' jobs because they are able to handle some of their difficulties such as non-disclosure of the patient's status and dealing with bereavement and stigma. As disclosing of a patient's status is a burden to volunteer caregivers, memory box making minimises the burden by providing the volunteer caregivers with the opportunity to deal with the issue and cope effectively. For example, recording and storing memories in the memory box helps people to break the silence surrounding the disease and death. Ebersohn et al. (2010) theorised that the making of memory boxes supports adaptation processes to build resilience. They view resilience as the ability to bounce back from adversity, through a process of adapting to changing circumstances. In the same study, these researchers have found that volunteers not only use their historical events to facilitate their personal growth experiences but also use memory box making to provide a space in which to grieve and disclose.

Ebersohn et al. (2010, p.79) further indicated that volunteers seem encouraged to explore their experiences and own their life stories through making lifelines. They use the lifeline to facilitate personal growth experiences within themselves as they are themselves clients struggling with specific aspects, such as being HIV positive, experiencing stigma, discrimination and isolation. Ebersohn et al. (2010) also added that they could learn from the memory box when referring to positive and negative life experiences.

## **2.8 CONCLUSION**

The literature reviewed indicates that most existing studies focus more on official formal caregivers of Aids than on volunteers, while studies on volunteers are scant. It is indeed surprising that little attention has been paid to volunteer caregivers' personal experiences with regard to the burden of HIV and Aids care. Although different ways of coping with the psychosocial challenges have been identified, volunteer caregivers have to re-evaluate their caregiving demands and resources, clarify values and priorities in order to cope with their unique challenges effectively. Caregivers experience varying types of burdens. They also encounter varying levels of access to financial resources and social support. Therefore, strategies for managing stress and burnout in order to promote self-care must be adapted to

their individual needs. In the next chapter, the researcher will outline the methodology used in this research in detail.



## **CHAPTER 3**

### **RESEARCH METHODOLOGY**

#### **3.1 INTRODUCTION**

The previous chapters highlighted the aims of this study, to explore both the psychosocial challenges and coping mechanisms of palliative care volunteer caregivers. It was evident that there is an urgent need for research into the psychosocial wellbeing of such caregivers working in the Aids arena as well as into interventions to improve their overall well-being. This was a way of generating knowledge on caregiver resilience as part of a growing body of literature pertaining to care given to the caregivers themselves. Therefore, Chapter 3 focuses on the guiding methodology of this study, namely, the procedures that assisted the researcher to achieve the research objectives. The aims of the study, the participants, the research design, the measuring instruments as well as the methods used for data analysis are addressed in this chapter. Lastly, this chapter concludes with the ethics adhered to during the research to protect the rights of the participants.

#### **3.2 AIMS AND OBJECTIVES**

This study set out to explore the psychosocial challenges and coping mechanisms of palliative care volunteer caregivers. It also investigated the needs and motivations of HIV and Aids palliative care volunteer caregivers caring for people living with Aids. Furthermore, this study determined the available resources and the type of support needed to help the volunteers cope with the experiences and challenges identified.

#### **3.3 RESEARCH DESIGN**

This study used a mixed methods approach to explore the psychosocial challenges and coping mechanisms of palliative care volunteer caregivers. McMillan and Schumacher (2010) indicated that researchers choose the approaches, variables and units of analysis, which are the most appropriate for finding an answer to their research question. The study design is comprised of a qualitative component in the form of semi-structured in-depth interviews with the said caregivers, as well as a quantitative component in the form of structured

questionnaires, within a single study, to understand the research problem more completely (David & Sutton, 2011). The rationale for mixing methods is that neither quantitative nor qualitative methods are sufficient by themselves to capture the trends and details of the situation such as the psychosocial challenges and coping mechanisms of palliative care volunteer caregivers caring for people with HIV and Aids. When used in combination, qualitative and quantitative methods complement each other and allow for a more complete analysis (Mertens, 2010).

Creswell and Plano (2011) highlighted three issues requiring consideration while designing a mixed methods study. They mentioned priority, implementation and integration. This study, however, used one of the most popular mixed methods designs in social research, a sequential exploratory mixed methods design consisting of two distinct phases. The first phase utilised a qualitative approach to collect data through individual, semi-structured interviews in order to obtain an in-depth understanding of the challenges faced by the said volunteer caregivers. Qualitative research assisted the researcher to develop a picture, analyse words, obtain detailed views of informants and conduct the study in a natural setting (Denzin & Lincoln, 2011). The second phase was the quantitative phase where the goal was to measure the level of stress perceived by the caregivers as well as to explore how they coped with the challenges they faced by using two measuring instruments.

Permission to conduct the research was requested from four organisations in Soshanguve. The criteria for selection of the organisation and participants as well as the purpose of the study were clearly explained to them. These criteria were as follows:

- The organisation had to be registered with the Department of Health. Organisations that were not registered were excluded.
- The organisation had to include palliative care volunteer caregivers doing home-based care to people living with HIV and Aids.
- The participants had to have been with the organisation for at least one year in order to qualify.

Two organisations met the requirements and received a follow-up visit from the researcher. Permission to conduct the study was obtained from the organisations (Appendix A refers) and suitable participants were identified. Accordingly, the researcher obtained permission from

the managers to address the volunteers about the study. In addition, permission to involve the latter as participants was obtained from them individually too.

### **3.4. PARTICIPANTS**

The population in this study refers to all caregivers in two Soshanguve HIV and Aids NGOs. A convenient sample comprising 24 palliative care volunteer caregivers participated in the study. Mertens (2010) contended that making use of purposive sampling enables the researcher to select relevant individuals who are informative. Hence, the participants were required to meet all the requirements in order to be considered for the study (Strydom & Delpont, 2011). The participants in the study were palliative care volunteer caregivers caring for people living with HIV and Aids. They were sampled from two organisations providing palliative care to people living with HIV and Aids in Soshanguve. One of the key requirements was that each participant should have worked for at least one year in the organisation. The participants should have been trained to provide services to people living with HIV and Aids.

The names of the organisations are Pfunekani Community Organisation and Umthombo Wempilo Service Centre. For the purpose of the study, the organisations are referred to as organisation A (Pfunekani Community Organisation) and organisation B (Umthombo Wempilo Service Centre). The population for organisation A consisted of 27 volunteers and 10 volunteers consented to participate in the study (this means that 37% of the caregivers in Organisation A participated in the study). Organisation B had 66 volunteers on their records of whom 14 participated in the study (this means that 21.2% of the caregivers in Organisation B participated in the study). From the 24 volunteer caregivers who participated in this study, 41.6% ( $n=10/24$ ) came from organisation A and 58.3% ( $n=14/24$ ) from organisation B. Accordingly, as noted, the researcher obtained permission from the managers to address the volunteers about the study (Appendix A). In addition, an information sheet was provided to them (Appendix B) and permission to involve them as participants was obtained from the volunteer caregivers individually and they also signed a consent form (Appendix C).

A biographical questionnaire was used to obtain relevant biographical information about the participants (Appendix E). Their ages ranged from 19 to 60 years. All were female. The majority of the participants were single, (71%;  $n=17/24$ ), followed by 25.0% ( $n=6/24$ ) who were married, with one person being a widow. The educational qualifications ranged from

12.5% (n=3/24) who had received primary education to 70.8% (n=17/24) who had undergone secondary education and 16.7% (n=4/24) who had attained tertiary qualifications. Table 3.1 below illustrates all the biographical information obtained from the participants.

**Table 3.1:** Biographical information of participants

| <b>Variable</b>       | <b>Item</b> | <b>Number &amp; % percentage<br/>of participants<br/>Total (n = 24)</b> |
|-----------------------|-------------|---|
| <b>Age</b>            | 19 -30 yrs  | 20.8% (n=5/24)  |
|                       | 31-50 yrs   | 75.0% (n=18/24)   |
|                       | 51-60 yrs   | 4.2% (n=1/24)   |
| <b>Gender</b>         | Female      | 100% (n=24/24)  |
|                       | Male        | 0% (n=0/24)   |
| <b>Marital status</b> | Single      | 70.0% (n=17/24)   |
|                       | Married     | 25.0% (n=6/24)  |
|                       | Widow       | 4.2% (n=1/24)   |
| <b>Educational</b>    | Primary     | 12.5% (n=3/24)  |
| <b>Qualification</b>  | Secondary   | 70.8% (n=17/24)   |
|                       | Tertiary    | 16.7% (n=4/24)  |

### **3.5 SAMPLING METHOD**

This study adopted a purposive sampling technique that entails the process of choosing respondents, based on specific features identified as selection criteria for the target population. Fouche and Schurink (2011) indicated that the main goal of such sampling is to include as much information as possible. Furthermore, purposive sampling refers to a type of sampling acceptable for social situations in which a researcher collects a small sample of specific cases and events for in-depth investigation of the problem being studied. Purposive sampling is also regarded by some researchers as “judgmental” sampling, as it is based entirely on the judgment of the researcher.

The judgment of the researcher entails making decisions about the sample and is guided by elements that contain the most characteristic, representative, typical attributes of the population that serve the purpose of the study best. Mertens concurs with this view (Mertens, 2010) when he contends that making use of purposive sampling enables the researcher to select relevant individuals who are informative. It is therefore important that the participants should meet all the requirements in order to be considered for the study (Strydom & Delpont, 2011). The research participants for this study were thus purposefully selected to seek typical and divergent data.

### **3.6 DATA COLLECTION METHODS**

Rabe (2009) indicated that the collection of data is generally purposive in a qualitative research design as cases are identified that will provide insight into the research problem. The method of data collection was explained to the participants. According to Doyle, Brady and Byrne (2009) it is very important that researchers determine the most suitable approach for answering their research questions, hence semi-structured, in-depth interviews were used as an information collecting method in this study. Fouche and Schurink (2011) describe interviewing as one of the main data or information collection methods in qualitative research. It is a way of accessing people’s perceptions, meanings and definitions of situations and construction of reality. The method gives the researcher and participants greater flexibility than a questionnaire. In addition, the researcher is able to follow up on particular, interesting avenues that emerge in the interview and the participant is able to provide a fuller picture where necessary (De Vos, Strydom, Fouche & Delpont, 2011). In-depth interviews

lasting approximately an hour as well as three self-administered questionnaires, including a biographical one, were used.

Participants were informed that the interview would be audio-recorded, after which they signed a consent form that gave the researcher permission to tape record the interview (Appendix D). A tape recording provides details at a level of accuracy that will not be possible by recalling information from memory alone. It is also better than note taking alone as the researcher can maintain greater eye contact with the participants using this method (Fouche & Schurink, 2011). The researcher administered the questionnaires shortly after all the participants had been interviewed. Questionnaires were self-completed in the presence of the researcher and in total took two days. The group from the first organisation completed these first while the other group from the second organisation completed theirs on the following day. The researcher was in the same room but occupied herself with something else. She tried to avoid a situation where participants discussed the questions; nonetheless, she also assisted them when they raised queries concerning the questionnaire.

Interviews and administering of questionnaires took place within the organisations where participants were volunteering their services. It has been suggested that interviewing within the organisations might be affected by particular circumstances. However, there seemed to be no better location option available since some participants indicated that they lived far away from the organisation and they were only willing to take part in the study if they could do it while they were on duty. In order to maintain consistency, all interviews and administering of questionnaires were therefore conducted in the participants' organisations. Participants were told that a short summary of the results of the study would be sent to their organisation, should they wish to be informed of the results. The measuring instruments and methods used for data collection are discussed below.

### **3.6.1 Measuring instruments**

To achieve the objectives of this study and to explore the psychosocial challenges and coping mechanisms of the said volunteer caregivers, the following methods and measuring instruments were used:

- Semi-structured in-depth interviews were conducted to explore the experiences and challenges of these caregivers. Participants were given the opportunity to talk about their

experiences and challenges of caring for people living with HIV and Aids, the strategies that they utilise to cope with the challenges, their needs and motivation for volunteering, as well as the resources that are available for them to make their jobs effective.

- To supplement the interview, two self-administered questionnaires were used. The *Perceived Stress Scale* was used to measure the extent to which these caregivers perceived aspects of their work and life as stressful. The *Coping Strategy Indicator* was used to measure the situational coping around the strategies of avoidance, problem solving and seeking social support of palliative care volunteer caregivers. These measuring instruments are discussed in more detail below.

#### **3.6.1.1 Semi-structured in-depth interviews**

A semi-structured, in-depth interview was used to explore the experiences and challenges of the caregivers in the HIV and Aids field. The interview provided an opportunity to gain a detailed understanding of their challenges with regard to caring for people living with HIV and Aids and the strategies they used to cope daily. The participants were given an opportunity to mention their needs and to make suggestions about changes that could be made in order to improve the standard of services in their organisations. The semi-structured in-depth interview completed the qualitative research design.

If a research study only uses the quantitative method, the lived experiences of participants will not be answered as such a method focuses on either true or false answers that are measured and statistically analysed. Hence, qualitative research was additionally used as it is “concerned with understanding and the subjective exploration of reality from the perspective of the insiders” (Fouche & Schurink, 2011, p.308). It intends to understand data to develop insights that explain and clarify phenomena such as relations, experiences, roles, points of view and organisations. Importantly, qualitative analysis aims to interpret the data to develop theoretical insights that describe and explain certain phenomena.

An interview schedule was developed and compiled based on information obtained from the literature reviewed. The schedule was then used to provide the researcher with a set of predetermined questions that were utilised as an appropriate instrument to engage the participants (De Vos et al., 2011) (Appendix F). The interview commenced with a short

briefing after which participants were given an opportunity to share a typical day of their lives in brief as an ice-breaking question. This also allowed the researcher to establish *rapport* with the participants. The researcher conducted all the interviews with them. The interview schedule consisted of 16 questions that guided the interviews as mentioned above. The participants were willing to discuss personal experiences and the researcher had more time to pursue areas of interest (Curtis & Curtis, 2011). A broad outline of the questions is provided below (cf. Appendix F for a full list of questions).

- What are the reasons for palliative care volunteer caregivers to help people who have Aids?
- What are the psychosocial challenges faced by palliative care volunteer caregivers caring for people living with Aids?
- What are the coping mechanisms used by palliative care volunteer caregivers caring for people living with Aids?
- What are the needs of palliative care volunteer caregivers caring for people living with Aids?
- Are there any available resources to help palliative care volunteer caregivers caring for people living with Aids?

After all the participants had been interviewed and all the necessary data had been gathered, the researcher then managed the data by organising and converting all the gathered data into file folders and computer files. The process is discussed under the section on data analysis. The two questionnaires are discussed below in more detail.

### **3.6.1.2 Perceived Stress Scale (PSS)**

The PSS questionnaire is a Likert-type scale and was developed by Cohen, Kamarck and Mermelstein in 1983 (see Appendix G). It was used to measure the extent to which volunteer caregivers perceived aspects of their work as stressful in this study. The original PSS is a 14-item instrument but a 10- and 4- item version of this scale is also available. The 10-item version of the PSS was used in the current study to measure the extent to which individuals perceived aspects of their work and life as stressful. The PSS has become one of the most widely used psychological instruments for measuring the perceptions of the stressfulness of a situation (Cohen et al., 1983). The items are easy to understand and were designed to determine how unpredictable, uncontrollable and overloaded respondents find their lives. The



scale also includes a number of direct questions about how individuals currently experience stress in their lives. The questions are of a general nature and may be applied to any population group (Cohen et al., 1983).

The PSS is not a diagnostic instrument, but is intended to provide a comparison between individuals in a given sample in terms of the stress they experience. The scale indicates many aspects of stress including the actual environmental experiences, subjective evaluations of the extent to which a situation is stressful as well as the biological responses to environmental experiences. Cohen et al. (1983) indicated that although the normative data on the PSS based on a 1983 Harris Poll of a representative U.S. sample are almost 30 years old, they may still be helpful in providing comparisons. Evidence for validity was corroborated by correlations between perceived stress and, for example, failure to quit smoking, failure among diabetics to control blood sugar levels, greater vulnerability to stressful life-event-elicited depressive symptoms and more colds. Concurrent and predictive validities and internal and test-retest reliabilities of the PSS were determined using scores from 446 undergraduates and from 64 senior students (mean age 38.4 years) participating in a smoking-cessation programme offered by the university of Oregon. The results showed that the PSS provided adequate reliability (Cronbach's  $\alpha=0.75$ ) and was a better predictor of the results of the problem under investigation (depressive and physical symptoms, utilisation of health services, social anxiety, and smoking-reduction maintenance) than were life-event scores. However, additional data indicated adequate reliability and validity of a 4-item version of the PSS for telephone interviews (Cohen et al., 1983).

Scoring of the PSS: Each item is rated on a 5 point scale ranging from “never” (0) to “almost always” (4). The total score of the scale was obtained by calculating the total scores of all the items after reversing four items (items 4, 5, 7 and 8). The total score was divided by the number of items in the scale (10) to make the interpretation of scores easier. The minimum score on the scale was thus 0 and the maximum 10. A high score on the scale reflected higher perceived stress. The coping strategy indicator questionnaire is discussed briefly below.

### **3.6.1.3 Coping Strategy Indicator (CSI)**

The CSI was developed by Amirkhan in 1990 (Appendix H refers) and was used to assess three basic modes of coping: problem solving, seeking social support and avoiding the event. This indicator was used to explore the coping strategies used by the participating caregivers

in this study. The problem solving scale assists individuals to plan and implement their strategies in solving problems. The seeking social support scale measures attempts of individuals to interact with one another, not necessarily for assistance in resolving the problem but simply for the comfort such contact provides. The last scale, avoidance, indicates individuals' tendencies to escape from the problem by means of both physical and psychological withdrawal (Amirkhan, 1990).

The CSI consists of 33 items, with three scales of 11 items each. The first scale assesses problem solving, which is an instrumental approach involving planning and implementation of steps to solve the problem. The 11 items completing the problem solving scale are Items number (2, 3, 8, 9, 11, 15, 16, 17, 20, 29 and 33) (Appendix H). The second scale concerns seeking social support, consisting of items number (1, 5, 7, 12, 14, 19, 23, 24, 25, 31 and 32). The third scale deals with avoiding the event, containing items number (4, 6, 10, 13, 18, 21, 22, 26, 27, 28 and 30) respectively.

In spite of its brevity, the CSI is used worldwide and has been translated into many languages. A long list of possible coping responses was administered to a large and diverse community sample. The participants selected a stressful event from their lives and briefly described it. They then responded to 33 questions with the event they described in their minds. The results indicated that participants cope with stressors in their lives using problem solving, seeking social support or avoiding the event. Even in community samples, the scales were found to be internally consistent (with Cronbach's alphas ranging from 0.84 to 0.93 (Amirkhan, 1990).

Convergent validity has been demonstrated when the scale is used in conjunction with other existing measures of coping, personality and pathology. Amirkhan further indicated that the criterion validity of the CSI's is demonstrated by its ability to predict actual coping responses made in both laboratory simulations and real-life situations (Amirkhan, 1990).

**Scoring of the CSI:** Obtaining the preferred coping strategy is achieved by calculating the total scores of all the items after scoring them. The numerical scores range from 1 to 3 (For example: *A lot* =3, *A little* =2 and *Not at all* =1). Three columns were provided (one column per coping strategy) and the scores for each question were entered in the appropriate column. The minimum score on the scale is thus 11 and the maximum score is 33. Each column was summed and the totals were entered in the appropriate boxes on the graph provided to

graphically indicate the preferred coping strategy (Appendix I for the scales, boxes and graph refers).

### **3.7 DATA ANALYSIS**

Data analysis is the process of bringing order, structure and meaning to the mass of collected, data (De Vos et al., 2011). The researcher first discusses the qualitative data analysis, followed by the quantitative data analysis.

#### **3.7.1 Qualitative data analysis**

As McMillan and Schumacher (2010, p.246) explained, “qualitative data analysis is primarily an inductive process of organising data into categories and identifying patterns and relationships among categories”. Fouche and Schurink (2011, p.308) provided a clear understanding of qualitative data, by indicating that “it is in the form of text, written words, phrases or symbols describing or representing people, actions and events in social life”. Data analysis enabled the researcher to make sense out of the raw data collected. In this study, the researcher critically examined the pages of field notes and interview transcripts in order to identify common themes in the participants’ descriptions of their real life experiences (Leedy & Ormrod, 2010).

The findings in the study were derived from the audio-recorded interviews. These findings were then transcribed in full and the transcripts were categorised into themes in terms of the purpose and objectives of the research. The researcher’s assistant edited the themes and validated that they were correctly categorised. In this regard, the researcher followed Creswell’s model of qualitative data analysis (De Vos et al., 2011) for this process. She employed a twofold approach where data was analysed in the field during data collection, while the second aspect involved data analysis, away from the field following the period of data collection previously alluded to. The following steps were taken: managing the data, reading transcripts and writing memos, generating categories, coding and interpreting the data, and representing and visualising. These steps are discussed below.

##### **3.7.1.1 Managing the data**

This phase came after all the participants had been interviewed and all the necessary data gathered. The researcher then managed the data by organising and converting all the gathered

data into file folders and computer files. She filed all the data based on the responses received in different questions from the semi-structured interviews (for example, all the data pertaining to *experiences* were grouped together, while the data pertaining to challenges and *coping* were also grouped together). The researcher then identified all the key issues, concepts and themes, in terms of which the data were examined and referenced.

The common themes among the questions were then grouped under the main themes as well as the sub-themes where appropriate. For example, the shortage or lack of material, the heavy workload and job related issues were grouped under the main theme *work difficulty* which fell under *challenges*. Personal challenges also contained themes such as *psychological and emotional challenges* with sub-themes *frustration, feelings of anxiety* and *anger*. Trying to solve a problem, praying, listening to music, talking about the situation, were grouped under the theme coping mechanisms. All the data related to each question was carefully organised and noted in order. This allowed for the exploration of any differences, similarities and relationships. The researcher reduced the data into small manageable sets of themes as mentioned above in order to write the final report.

### **3.7.1.2 Reading transcripts and writing memos**

The researcher read the transcripts several times in their entirety, to gain a sense of the interviews before separating the data into different parts (De Vos et al., 2011). Furthermore, she undertook minor editing where necessary to make the field notes retrievable and generally cleaned up what seemed overwhelming and unmanageable. According to Mertens (2010), analytical memo writing should start shortly after the commencement of data collection and should continue until the final research report is completed. The researcher therefore wrote some notes about the coding process, which consists of memos in the form of short phrases, ideas or key concepts.

### **3.7.1.3 Generating categories, coding and interpreting the data**

De Vos et al. (2011) indicated that identifying significant themes, recurring ideas and patterns of belief that link people and situations, is the most intellectually challenging phase of data analysis and one that could integrate the entire process. The researcher identified meanings and then divided them into categories and allocated codes. Different colours were used to indicate various categories, with the same ideas being coded in the same colour. The

researcher read through the colour-coded information to check for any misplaced data. She then continued to organise information into meaningful sections by grouping common factors together. New categories were identified and data that were consistent in all the categories were recorded. Information that did not add any value to the study was omitted. This process involved reducing the data to small manageable sets of themes in order to write the final report. In addition, she refined the data to interpret the meaning of the categories. Mertens (2010) pointed out that interpreting involves making sense of the information or the lessons learned; hence the researcher stood back to be able to form an overall opinion of the gathered data and from this stance, interpreted them accordingly.

#### **3.7.1.4 Representing and visualising**

This is the final stage of the data analysis process; the researcher presented all relevant information until all the themes were saturated. This presented a challenge because she needed to come to terms with the fact that it was not feasible to present all the data, but needed to be selective in terms of what she wanted to present. She also acted as an editor, by identifying key parts of the data and prioritising certain parts instead of others (De Vos et al., 2011); the data were therefore presented in terms of themes and sub themes. Quantitative results were used to complement and extend the qualitative findings.

#### **3.7.2 Quantitative data analysis**

Curtis and Curtis (2011) indicated that data analysis is a specialised area with regard to research procedures; therefore, researchers should acquire knowledge of the statistical techniques that are suitable for their research studies. To determine to what extent the questionnaires contribute to our understanding of the psychosocial challenges and coping mechanisms of the volunteer caregivers who participated in the semi-structured, in-depth interviews, a particular procedure was adhered to. The researcher gathered all the completed questionnaires in order to convert the raw data into meaningful or interpretable information. She then edited and encoded the data to eliminate errors that may have occurred during the process on a spreadsheet programme (Microsoft Excel) required to record the raw data on the computer. Furthermore, the researcher recorded all the information from the biographical questionnaire, assigning certain numbers to variable attributes. For example, when coding the data, she coded male as 1 and female as 2 while each category of a variable with missing information was coded as 0. A short description of a coding procedure and the location of

data for variables were also recorded. The researcher then placed the data into categories to facilitate their organisation and interpretation. The descriptive data analysis technique was used in the study as it provides an overall, comprehensive and straightforward picture of a large amount of data.

#### **3.7.2.1 The Perceived Stress Scale used in this study**

The participant's scores obtained from the PSS were calculated and added together to determine a total score. The total score was then divided by the total number of participants in order to obtain the mean score. The latter score was an indication of how the participants perceived stress in their lives. The results were then compared with the information obtained in the semi-structured interviews about the experiences and challenges to establish whether there was a correlation. The results are addressed in the next chapter.

#### **3.7.2.2 The Coping Strategy Indicator used in this study**

The CSI consists of three scales, as mentioned above. All the sections were calculated and added in the appropriate spaces to identify which coping strategy was dominant for each participant. The scores of participants were also calculated to obtain the mean score. This was therefore compared to the data obtained in the semi-structured interviews about the coping mechanisms of palliative care volunteer caregivers. The researcher compared information from the interviews and the CSI to determine if there was a correlation between them. The results from the measuring instruments were then combined with the interpreted data from the interviews to enhance the trustworthiness of the information obtained.

### **3.8. PILOT STUDY**

De Vos et al. (2011) argued that it is important to conduct a pilot study for a qualitative or a quantitative study. A pilot study is usually undertaken in qualitative research where a few participants, possessing the same characteristics as those of the main investigation, are involved in the study to ascertain certain trends. The main purpose of a pilot study is to determine whether the relevant data will actually be obtained from the actual participants (Strydom & Delport, 2011). Once the interview schedules had been compiled, the researcher arranged for six participants in the two identified organisations to pilot test the interview

schedules. Accordingly, those schedule questions that were not clear and did not contribute to collecting the relevant data, were adjusted by the researcher, prior to the main investigation.

In quantitative research, the reliability and validity of the instrument are very important for decreasing errors that might arise from measurement problems in the research study (Mertens, 2010). Hence, in this study the instruments were pilot tested with six participants who did not form part of the selected group. The goal was to validate the instruments and to test their reliability. The said pilot study revealed that the participants were struggling with the English language. The researcher had to translate the interview schedule and all the questionnaires into the language which they best understood, Setswana. It is acknowledged that translation has pitfalls such as misconstruing meaning. A specialised translator who possessed a sound knowledge of both English and Northern Sotho was asked to help with the translations. The translation was carried out together with the researcher, who is also conversant with both languages. The results of the pilot study helped to establish the stability and internal consistency, face and content validity of the questionnaires.

### **3.9. FEASIBILITY OF THE STUDY**

Strydom and Delport (2011) point out that the feasibility of a study is centred on practical considerations of what may be accomplished within a specific period and with limited resources. Considering the above-mentioned factors, the researcher considered the study to be feasible as it was conducted with Soshanguve NGOs in the area where the researcher resided. The participants were easily accessible since they already worked in the organisations. The researcher also had enough time to talk to the participants and conduct the interviews. Permission was readily obtainable from the management of the NGOs for involving the caregivers since a relationship had already been established. Permission was also obtained from the participants themselves, as discussed above.

### **3.10. ETHICAL CONSIDERATIONS**

Ethics are an important part of the research design, especially in areas that frequently deal with issues that are sensitive both in terms of their personal meanings for research participants and their relevance to controversial issues (Atkins & Wallace, 2012). These authors furthermore indicated that research ethics provide researchers with a code of moral guidelines regarding how to conduct research in a morally acceptable way. The proposal for

the study was evaluated for adherence to appropriate standards in respect of ethics according to the Department of Psychology at the University of South Africa and was unconditionally approved by the ethics committee. A briefing session was set up with caregivers in each organisation; participants were briefed about the study and an information letter was given to each of them (Appendix B refers). While conducting this study, the researcher paid attention to the following ethical considerations: informed consent, permission to tape-record the interviews, confidentiality and anonymity, avoidance of harm to respondents, deception, actions and competence of the researcher as well as the release of findings. These are now considered individually.

### **3.10.1 Informed consent**

As Atkins and Wallace (2012) emphasise, the principle of informed consent requires the investigator to provide all the information about a proposed study so that individuals can make a rational, informed decision regarding their possible participation in it. Accordingly, the researcher wrote a letter to the managers of the two organisations where she intended to carry out research, requesting their permission to do so. The necessary information concerning the study, such as its purpose, the procedures that would be followed during the research and the possible advantages and disadvantages were clearly outlined. The researcher provided accurate and complete information, so that the participants could understand the details of the investigation fully, for them to make a voluntary and thoroughly reasoned decision about their possible participation (Strydom & Delpont, 2011). She also included information on the use of audio recordings so that participants would not be surprised on the day of the interviews. The participants also signed a letter of informed consent as an agreement to participate voluntarily in the study as well as permission to tape-record the interviews (Appendix C and D refer).

### **3.10.2 Confidentiality**

According to Neuman (2011, p.139) “confidentiality is the ethical protection for those who are studied by holding research data in confidence or keeping it secret from the public, not releasing information in a way that permits linking specific individuals to specific responses”. Anonymity is also important: because participants remain nameless, their identity is protected from disclosure and remains unknown. Participants were assured of their right to confidentiality; their right to terminate their involvement in the study at any time was also



stipulated in their information letter. The researcher ensured that the participants did not use their real names and that their personal information was not divulged in the research. For this reason, they were allocated a code so that data collected from them could not be linked to their identities.

### **3.10.3 Avoidance of harm**

Strydom and Delport (2011, p.115) warn that participants may experience concrete harm, for instance, with regard to their employment situations. The researcher was aware that certain issues could arise from individual interviews that could cause participants emotional harm. They were provided with information about the resources available to them should they wish to attend counselling. An information sheet was made available to the participants that provided them with information about the counselling centres. However, the researcher followed the fundamental ethical rules of social research of avoiding harm to participants. After every session, the researcher debriefed each participant to ensure that no harm or even any potential risks of emotional harm due to the research process had occurred.

### **3.10.4 Deception**

Curtis and Curtis (2011) mention that deception in research often entails pretension by the researcher regarding the nature or purpose of the research and by providing misleading information and withholding information from participants in such a way, that if they had been aware of the real nature of the study, they might have declined to participate. Accordingly, the researcher discussed the aim of the study and participants were given truthful information from the beginning of the research process. No participants were bribed or paid to participate in the study. Furthermore, as noted, accurate information pertaining to the study was given to the participants and they were not coerced into agreeing to participate.

### **3.10.5 Actions and competence of the researcher**

Researchers should be competent, honest and adequately skilled to undertake the proposed investigation (Curtis & Curtis, 2011). The researcher has experience of working as an HIV and Aids counsellor, facilitating support groups and conducting interviews. In addition, she also worked under supervision conducting the research according to the procedures agreed upon with her supervisor.

### **3.10.6 Release of findings**

Atkins and Wallace (2012) stated that a research report is the medium through which a completed study is described to other people, whether they are colleagues at work or a worldwide audience. They defined a research report as a written document produced as a result of procedures undertaken to reveal information. It can also be viewed as a final product of a long research process that has now been completed. In this study, findings are being released in the form of a full dissertation, which is being submitted to the Department of Psychology, University of South Africa, for degree purposes.

### **3.11. CONCLUSION**

The aim of this chapter was to give a detailed explanation of the research methodology used in this study. Both the qualitative and quantitative methods used to measure the psychosocial challenges and coping mechanisms of palliative care volunteer caregivers are described. The results of both the in-depth interviews and the two questionnaires are discussed in detail in the next chapter.

## **CHAPTER 4**

### **RESEARCH RESULTS**

#### **4.1 INTRODUCTION**

In this chapter, the findings from the two measuring instruments (the PSS and the CSI) as well as the results of the interviews with the caregivers are discussed. Biographical details as well as details about the working environment of the caregivers are provided.

#### **4.2 REVIEW OF THE OBJECTIVES**

Before discussing the results, it is important to review the objectives of the research. The first objective was to explore the reason why palliative care volunteer caregivers volunteered to help people with Aids. The second objective was to explore the psychosocial challenges faced by them. The third objective was to explore the coping mechanisms used by the caregivers. The fourth objective was to identify their needs and lastly to identify the resources available to them. As mentioned previously, two questionnaires (the PSS and the CSI) were used to supplement the interview data.

The findings of the analysed quantitative data (in terms of working environment, PSS and CSI) and the findings of the analysed qualitative interviews are addressed below.

#### **4.3 THE WORKING ENVIRONMENT OF THE VOLUNTEER CAREGIVERS**

This section presents the results of the training of the volunteer caregivers<sup>1</sup> as well as their length of time in working for the organisation, the number of patients they see and whether or not they belong to support groups.

All the participants had received some form of formal or informal training to work as caregivers in the respective organisations. The majority of the caregivers (58.3%; n=14/24) received formal training, while 41.6% (n=10/24) received informal training, mostly in the form of in-house training at the organisations where they were working. The duration of the training varied greatly, with the shortest training lasting 3 weeks and the longest training taking 12 months. The types of training included 12.5% (n=3/24) of participants being trained

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<sup>1</sup> The study is about palliative care volunteer caregivers; however, for the sake of brevity, the researcher uses the term “volunteer caregivers” in the next sections.

in Auxiliary nursing, while 41.6% (n=10/24) were trained in HIV/Aids care. Almost half of the participants (45.8%; n=11/24) had received 69 days training in home-based care. None of the participants who indicated that they received training in palliative care specifically, except that it was part of the training for those who had been trained in home-based care and auxiliary nursing.

The average length of time that participants worked for the respective organisations ranged from one to ten years. Almost forty two percent of the participants (41.6%; n=10/24) were with the organisation for one to four years, while 45.8% (n=11/24) had been with the organisation for five to eight years and 12.5% (n=3/24) had been there for between nine to ten years.

The participants had many patients to take care of and their patients were seen on a daily, weekly, or on a monthly basis. The majority of the participants (54.2%; n=13/24) took care of between nine and ten patients, while 20.8% (n=5/24) had between seven and eight patients. Twenty five percent (n=6/24) cared for between eleven and fourteen patients.

The majority of the caregivers (63.6%; n=14/22) did not belong to any support group, whereas 27.2% (n=6/22) belonged to a support group, which was not part of the organisation with which they were working. Two participants left this question unanswered. The results on the working environment of the caregivers are summarised in Table 4.1 below.

**Table 4.1:** Working environment of the participants

| <b>Variable</b>                         | <b>Item</b>        | <b>Number &amp; percentage of participants<br/>Total (n = 24)</b> |
|---|--------------------|---|
| <b>Type of training</b>                 | Formal training    | 58.3% (n=14/24)   |
|   | Informal training  | 41.6% (n=10/24)   |
| <b>Duration &amp; training</b>          |                    |   |
| 12 months                               | Auxiliary nursing  | 12.5% (n=3/24)  |
| 3-5 weeks                               | HIV/ Aids training | 41.6% (n=10/24)   |
| 69 days                                 | 69 Days training   | 45.8% (n=11/24)   |
| <b>Duration working at organisation</b> |                    |   |
|   | 1-4 yrs            | 41.6% (n=10/24)   |
|   | 5-8 yrs            | 45.8% (n=11/24)   |
|   | 9-10yrs            | 12.5% (n=3/24)  |
| <b>Number of patients per caregiver</b> |                    |   |
|   | 7-8 patients       | 20.8% (n=5/24)  |
|   | 9-10 patients      | 54.2% (n=13/24)   |
|   | 11-14 patients     | 25.0% (n=6/24)  |
| <b>Member of support Group</b>          |                    |   |
|   | Members            | 27.2% (n=6/22)  |
|   | Non-members        | 63.6% (n=14/22)   |
|   | No indication      | 8.3% (n=2 /24)  |

Note: Two participants left the question about “member of support group” unanswered. Hence there are only 22 participants recorded on the table instead of 24 participants.

#### 4.4 PERCEIVED STRESS SCALE

The PSS measured the extent to which volunteer caregiver’s perceived aspects of their work as stressful, with a score of 0 meaning that perception of stress was very low, and a score of 4 indicating a high perception of stress. The mean of the PSS scale was 1.98 with a standard deviation of .436. The minimum score on the scale was 1.40 while the maximum was 3.20 (n=24). The results of the PSS indicate that the caregivers who participated in this study perceived their work only as mildly stressful.

The only variable that significantly correlated with the PSS was age, with younger caregivers perceiving their work as more stressful than older caregivers ( $r = -.410$ ;  $p = .046$ ).

#### 4.5 THE COPING STRATEGY INDICATOR

The CSI gives an indication of the type of coping mechanism caregivers use to cope with their daily challenges in the work situation. The results indicated that the majority (45.8%;  $n=11/24$ ) used “avoidance of the problem” as a coping strategy. “Problem solving” as a coping strategy was used by 29.2% ( $n=7/24$ ), while “seeking social support” was used by 25.0% ( $n=6/24$ ) of them (Figure 4.1). This finding indicates that most volunteer caregivers in this study employ avoidance of the problem as their coping strategy. As may be expected from the literature (Kang’ethe, 2009), their chosen strategy is not very effective because they still experience stress while doing their job. Avoiding the problem instead of solving it helps for only a short period of time before the problem reappears. This might lead to volunteer caregivers constantly experiencing some level of stress in the HIV and Aids field, due to a lack of effective coping mechanisms.

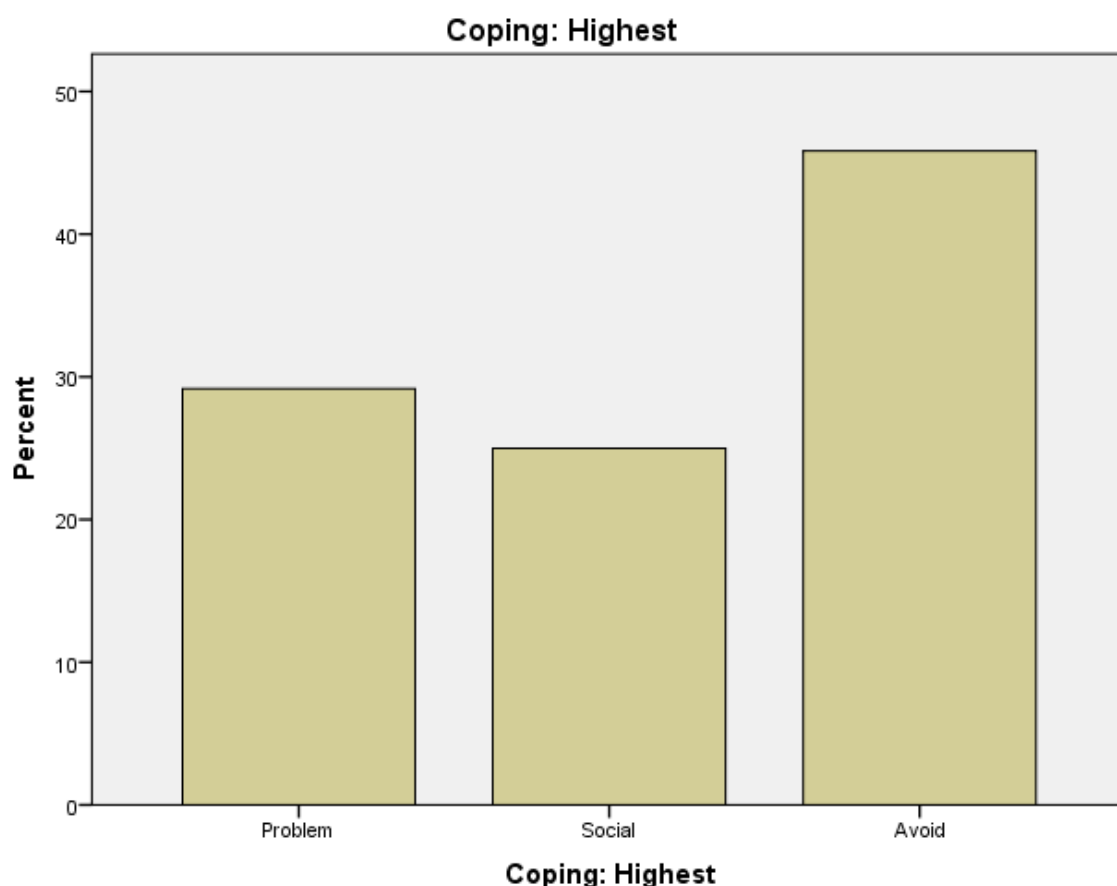


Figure 4.1 Coping strategies used by caregivers ( $n = 24$ )

There were no findings of significant differences between any of the variables and the CSI, probably due to the low number of participants. There was, however, a tendency for caregivers who cared for more patients and thus had a higher workload, to use avoidance of the problem as their coping strategy (Table 4.2), while those with less patients tended to make use of social support as a coping strategy. As may be observed from Table 4.2, 50% (n=3/6) of caregivers who cared for between 11 and 14 patients, and 61.5% (n=8/13) who cared for 9 to 10 patients, utilised avoidance of the problem as a coping strategy. None of the caregivers who cared for a lower number of patients (between 7 to 8) employed avoidance of the problem as coping strategy, while 80% (n=4/5) of them made use of seeking social support as their coping strategy. These results indicate that volunteer caregivers who experience a heavy workload have problems coping with their stress and they tend to ignore or avoid their problems to relieve it; an unhealthy situation, which might lead to burnout if not rectified. It should however be noted that about a third of participants who experienced a heavy workload utilise problem solving as coping strategy (30.8%; n=4 and 33.3%; n=2 of caregivers who cared for 9 to 10 and 11 to 14 patients respectively).

**Table 4.2: Cross-tabulation between number of patients and coping strategy used**

| <b>Number of patients</b> | <b>Problem solving</b> | <b>Social support seeking</b> | <b>Avoidance of problem</b> | <b>N</b> |
|---------------------------|------------------------|-------------------------------|-----------------------------|----------|
| <b>7 – 8</b>              | 20% (1)                | 80% (4)                       | 0% (0)                      | 5        |
| <b>9 – 10</b>             | 30.8% (4)              | 7.7% (1)                      | 61.5% (8)                   | 13       |
| <b>11 – 14</b>            | 33.3% (2)              | 16.7% (1)                     | 50% (3)                     | 6        |
| <b>N</b>                  | 7                      | 6                             | 11                          | 24       |

The results of the interviews are addressed in terms of the research objectives discussed in Section 4.2.

#### **4.6 VOLUNTEER CAREGIVERS' EXPERIENCES OF THEIR ROLE**

The volunteer caregivers reported certain experiences associated with their role as caregivers. An investigation revealed themes such as their daily responsibilities as well as their positive and negative experiences regarding caregiving, a discussion of which follows next.

#### 4.6.1 Daily responsibilities

Volunteer caregivers were asked to explain their daily responsibilities with reference to their caregiving role. They indicated responsibilities such as bathing, feeding, cleaning, gardening, recording vital signs, cooking, rubbing and massaging the patients, referrals, counselling, praying and guiding the patients and families as well as collecting medication from the clinic. Some participants commented about their daily responsibilities as follows: *“If there are sicknesses that need a clinic I refer the patient. Sometimes there is nobody to help the patient; we need to be there every day to take him/her outside in order to get fresh air”* (P20<sup>2</sup>); *“Sometimes I have to escort my patient to the clinic for check-up when there is nobody in the family”* (P2); *“We are usually grouped in a group of five to do gardening for our patients to get some food”* (P11); *“When the patients agrees I pray with them and their families before I leave the house, but others refuse and I do not force them”* (P8).

Volunteer caregivers were also often required to do household tasks such as cleaning and cooking for the patients as one of their responsibilities. They responded as follows in this regard: *“Some of my patients stay alone and are in category 3 (bedridden) so I have to assist them with cooking, bathing and cleaning”* (P9); *“I cook and clean for the patient when necessary, it depends on the condition of the patient for that day”* (P10). It is evident from the responses that volunteer caregivers do not only clean, cook and bath the patients; they also have to perform other duties that they encounter while doing their job such as collection of cards at the clinic and reminding the patients about consultation dates.

Some of the responsibilities performed by the volunteer caregivers included nursing care and psychological tasks such as giving medication, checking if patients were taking their medication correctly, recording vital signs and doing counselling. Some participants responded as follows about these tasks: *“I clean and dress their wounds and also collect their (TB) cards at the clinic and remind them of the dates of consultations”* (P9); *“I also take vital signs, give them counselling and guide family members; it helps me to observe their condition by talking to them”* (P12); *“I sometimes counsel them and also give them guidance about their grants money and where to apply”* (P1); *“For those who cannot do it for themselves, I have to give them counselling, collect medication from the clinic and check if they follow*

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<sup>2</sup> Participants were allocated codes to protect their identities. P1 stands for Participant 1, P2 for Participant 2 etc.



*instructions about their treatment*” (P19). It is evident that most of the time volunteer caregivers go beyond their call of duty to assist their patients.

#### **4.6.2 Positive experiences associated with caregiving**

The volunteer caregivers reported experiencing some positive aspects associated with their role as caregivers. Some of these experiences were the support provided to caregivers by family members, trust by patients and the recovery of patients. These experiences are discussed below.

##### **4.6.2.1 Support by family members**

The volunteer caregivers in this study stated that there were some families that were very understanding and provided full support to them and their patients. Some of the experiences are indicated below: *“When you arrive and find that the family already bathed the patient it feels good”* (P20); *“With the support of the families to see critical patients improving, standing up and work again makes me happy”* (P6) *“I feel relieved when I only have to take vital signs and give the patient medication when the family is there to help”* (P9); *“Some family members will tell you that they will take care of the patient over the weekend so I should not stress and I feel so relieved”* (P15). The findings above indicated that volunteer caregivers were well accepted by some patients’ families and this gave them an opportunity to discuss confidential issues such as the cause of the illness and other issues affecting the family when caring for people living with HIV and Aids.

##### **4.6.2.2 Caregiver being trusted by patients**

Some of the patients became comfortable with having caregivers around and wanted to know more about the disease and how they could be assisted. They shared their feelings and thoughts, and the volunteer caregivers became attached to the patients because the latter made their jobs easier. Some reflected as follows: *“I have bonded with my patients and they trust me, they listen to my advice”* (P3); *“It is so good to be trusted, to see your patients’ following your instructions and being discharged at the clinic to be with their families”* (P12); *“They trust me they even send me to withdraw money for them at the bank ATM instead of their children or other family members”* (P23); *They share their deep secrets with me, they also complain when I leave saying why don’t you stay longer? And it is not possible because I*

*have to see other patients” (P19); “They trust me, we have a good relationship, they sometimes invite me for tea or to the parties of their relatives” (P20).* It is clear that some patients trust their caregivers more than their family members. Some of the patients would offer the caregivers tea. Many complained that the volunteer caregiver’s stay was too short, and they said that they would love to see the caregiver every day. Some of the patients also wrote moving letters of gratitude to their caregivers.

#### **4.6.2.3 Recovery of patients**

Another positive experience for volunteer caregivers is the recovery of their patients. They said that when they see their patients recovering and fighting the disease it is a joy to them. For example: *“When patients adhere to their treatment and improve their condition I feel so pleased” (P8); “I see my patients as fighters, it feels so good to see them recovering from their conditions” (P18); “It feels so good when a recovered patient calls you and say how are you? When are you coming? Instead of you calling him or her” (P22).* Another participant said: *“When a bedridden patient become cooperative and take medication, stand up and walk again it is a nice feeling. I feel satisfied that I have done my job” (P5).* It is evident from the responses that caregivers feel very satisfied when their patients recover from their sicknesses.

#### **4.6.3. Negative experiences associated with caregiving**

Participants also mentioned a number of negative aspects associated with their caregiving role, such as being ridiculed by their communities, undermined by other caregivers, negligence of patients by their families and over-identification with their patients.

##### **4.6.3.1 Volunteer caregivers ridiculed and undermined**

Some participants indicated that it is difficult to walk around in the community because there are people who undermine and criticise them. They mentioned that they are even afraid to pass through some of the streets as there is invariably a group of men who ridicule them. For example, one participant said: *“We are afraid to be raped by these men even though we walk in pairs” (P4).* They shared their feelings of being intimidated on the streets, for example: *“They ridicule us on the streets, calling us names such as, “nurse bandages, “sister condoms” and it is so embarrassing” (P22); “Others criticise us saying, are you nurses? You give people condoms do you also use condoms? You think you are smart maybe all of you are*

*sick and it is so disturbing” (P6); “They laugh at us, when we pass they ask for condoms while others say they cannot use government condoms because they have worms” (P10).*

Certain participants felt undermined by their employers and co-workers as well as by patients and their family members. Some shared the following: *“We feel undermined as older caregivers as most of the time we are segregated, younger caregivers attend trainings most of the time while we remain behind” (P2); “Some patients and their families undermine our work, they prefer nursing sisters from the clinic than us and professional nurses are not always available as they work in the clinic full time, it is so discouraging” (P15).* One participant found it hard to work with male patients. She reflected as follows: *“It is difficult to work with male patients. They do not want us to help them, they have negative attitude towards us” (P24).* It is clear from the findings above that although caregivers are doing their best to assist the patients on a daily basis, some community members do not understand their role and do not appreciate what they do. They humiliate them on the streets and make them feel belittled and vulnerable in their own communities. It disheartens volunteer caregivers further if they are treated as inferior by other caregivers because they are volunteers.

#### **4.6.3.2 Patient neglect by family members**

A further negative experience that participants commented about concerns families who neglected their patients and did not care for their well-being. They were therefore not helpful in ensuring their patients’ full recovery. There were cases where patients told the caregivers that they (the caregivers) were often the only people who dressed their wounds. They also reported bathing themselves while their families did not assist them with anything. This was evident when the caregivers visited and found that the patients were in the same clothes, soiled and in a much worse condition than before. Some of the experiences are highlighted below: *“I sometimes come across a situation where my patient is very sick but refuses to go to the clinic. That makes me feel bad because families does not encourage their sick people to go to the clinic and they suffer in pains” (P19); “I have some patients who have family members who refuse to take care of them when I am gone, they are arrogant, they say it’s my job I should do it,” (P1), “It is so painful when it’s weekend. There are families that do not care about their patients. You find him/her lying in soiled blankets and in bad condition sometimes” (P10).* Other volunteer caregivers also highlighted that *“Families are not involved in care, patients suffer while they are there waiting for us to do the job. It is so painful when you come after the weekend and you find the patient in the same position you*

*left her in on Friday and she had developed terrible bed sores” (P2); “I would request the nursing sisters at the clinic to give the patient a return date during the week instead of Friday or Saturday because then I had to escort him/her and it became difficult for me. Some family members refuse to assist even on a weekend; they say we were not there when the person gets HIV” (P24).* It was further very hard for the volunteer caregivers that some of the family members viewed them as outsiders and refused to help them in any way. It is clear that caregivers, at times, overstepped the boundaries of duty to assist their patients. It is, however, extremely important for caregivers to be able to maintain their separateness, which seemed to be hard for them as they developed a close bond with their patients. The refusal of family members to assist the patients might be an indication that the families are still angry with them for being infected with HIV. It thus becomes the volunteer caregiver’s burden as they have to do everything for the patient.

#### **4.6.3.3 Over-identification with patients**

Volunteer caregivers often over-identified with their patients and often could not make a clear distinction between their work and their private lives. They reflected as follows: *“It is so difficult when your patients are very sick. I end up thinking about them even when I am at home” (P2);* another participant said: *“Sometimes I do not sleep thinking about my patients, I end-up going to see some of them on weekends” (P6); “When it’s a holiday and your patient is very sick it is so painful, it’s your burden you think about it even at home” (P13).* Over-identification with their patients is clearly a problem for volunteer caregivers, and they often end up assisting patients on weekends and during holidays. This affects their own personal and family lives negatively and can have a detrimental impact on their wellbeing. Volunteer caregivers should be assisted in drawing the line between work and personal lives.

### **4.7 REASONS WHY PALLIATIVE CARE VOLUNTEERING IS IMPORTANT**

The question “Why is your role as a palliative care volunteer caregiver important to you?” was asked to determine what motivated volunteer caregivers to do the work that they did. Most of the participants were motivated by various reasons. The most common were a desire to help and receive recognition; exposure to trauma and being affected by HIV and Aids, job opportunity, being inspired by others, making a difference and out of sympathy and guilt. The themes that emerged in the current study are discussed in more detail below.

#### **4.7.1 Desire to help and recognition**

Most of the research participants indicated that they viewed their job as meaningful and important because they were helping community members who were ailing. Some participants indicated that they were interested in helping others and expressed a desire to see people healthy and well. Some participants reflected as follows about their motivation to volunteer as caregivers: *“I love people; I love to see people being assisted. When I go to the clinic people are there on the benches with nobody to assist them”* (P18); *“I wish to see people recover when they are sick”* (P9); *“I decided to volunteer when the opportunity arise to help people, to help with campaigns and to educate people about the disease”* (P4).

Some participants indicated that when community members notice the importance of the work they do, it motivates them to work even harder. This is what they said: *“When community members come to say thank you, it feels so good, at least we are recognised”* (P2), *“I like it when some of the community members appreciate us especially in their community meetings at the end of the year, it shows that indeed we worked hard”* (P10). They also reported that being loved and appreciated by patients and families motivates them. For example: *“I feel great, some of my patients still need me, they call me even when they are well and discharged from our list”* (P11); *“They feel good they call you when you did not come and that feels good”* (P15). This indicate that volunteer caregivers have realised that there are many people who are suffering and do not know what to do, but because they love people they decided to volunteer in order to assist them.

#### **4.7.2 Exposure to trauma and being affected by HIV and Aids**

A number of participants said that being exposed to trauma themselves motivated them to volunteer as caregivers. They reported helping or caring for relatives, family members, and friends who had been near to death or had died of the disease. They commented as follows: *“I took care of my grandmother, she was suffering from stroke and nobody knew what to do when she became very sick”* (P24); *“I saw some cases where children become neglected by parents when they are HIV positive, by volunteering it opened the doors for me to assist them through our organisation”* (P13). Another caregiver said: *“One of my friends was very sick and I could not handle the situation. Then I stopped visiting her, but she recovered later but the friendship was not that good anymore. I was so traumatised as it was for the first time to*

*see a person with Aids, but that opened my eyes to assist others instead of running away”* (P3) .

Some participants indicated that they had witnessed their family members, relatives and friends die of Aids with little support from the people around them. Others had friends and family members living with HIV, while, as mentioned, others were HIV positive themselves. Some of the participants reflected as follows on their experiences: *“My uncle and cousin died of HIV and there was nobody to assist as we all did not know anything about the disease”* (P21); *“The way I have been raised as an orphan made me wish to care for other people who are sick. I know the pain of losing a loved one”* (P8); *“One of my friends was HIV positive and passed away, it was so painful, I did not know anything about the disease; I would go there but do nothing”* (P1). This shows that volunteer caregivers were drawn to this type of volunteer job in home-based care as some of their family members had died from HIV and Aids. They felt that they could have helped their family members better if they had had the expertise during that period of need. That is how they ended up training and volunteering in home-based care.

#### **4.7.3 Job opportunity**

Certain participants reported volunteering their services with the hope of securing permanent employment. They expressed a need to improve their skills and obtain remuneration or better paying jobs in future. They reported as follows: *“I always wanted to help the community, and when the opportunity comes I decide to volunteer with the hope to get paid when funds are available”* (P16); *“I wanted to do nursing but could not afford it so I saw volunteering as another opportunity. I am worried now because I see myself growing old in this organisation and nothing is changing”* (P20); *“I volunteered in a hospice first and then came here as it is near to where I stay with the hope to get a job in future. I am growing old now and I’m still doing the same job, no improvement”* (P5).

Acquiring skills and experience with regard to health care, as well as obtaining a job in future, attracted many participants to volunteer work. There was, however, a great deal of frustration associated with minimal opportunities for growth at the organisations, especially for the participants who had worked there for many years.

#### **4.7.4. Inspired by others**

Some volunteer caregivers indicated that they had been inspired by other caregivers who did the same work. When their family members, relatives and friends were sick, there were caregivers who came to assist the family. They recounted their views as follows: *“My sister was sick and there were caregivers from Olerato Home-based care organisation who use to come and take care of her. I was so impressed and I started enjoying what they were doing”* (P12); *“I felt that when you are at home doing nothing is not good, so I decided to join my friends and volunteer to help people”* (P7); *“My father was very sick and my mother was required to replace my father at work, caregivers use to come and assist us, I would have to take over when they are gone as my mother was working”* (P22). It is clear that participants believed that if some people were able to assist others who were not even their family members, how could they fail to do the same? Hence they decided to volunteer their services and give something back to their communities.

#### **4.7.5. Feelings of a guilty conscience**

Some participants reported volunteering their services with the hope of easing their guilty feelings. They reported that they had failed to help or care for family members and friends who died of the disease, and they blame themselves. They reflected as follows in this regard: *“I had a boyfriend who was very sick and I could not help him as I did not have any knowledge and information. I came to volunteer because I feel guilty; I want God to forgive me”* (P15). Another participant said *“My sister was sick and I did not do anything to try and help, until she passed away and I feel guilty about my ignorance. I decided to volunteer to ease the guilty conscience.”* (P8); *“My uncle and cousin died of Aids and there was no support, I felt responsible. I was there watching them suffer every day until they die. I promised my cousin I will learn about the disease and try to help others”* (P10). It is evident that some volunteer caregivers were regretful and felt guilty about the sick people and their late loved ones because they did not do anything to assist them. Moreover, they felt unable to forgive themselves; hence they tried to work with the sick people to ease their conscience.

#### **4.7.6. Making a difference and being sympathetic**

Volunteer caregivers are mainly inspired by social respect and moral duty. Participants acknowledged that people living with HIV need their support and believe they can make a

difference in their lives, as was testified to by some of the participants. They commented as follows: *“I wanted to drop out when I realise that there is no money but seeing that we make a big difference in people’s lives that motivated me to continue despite the money issue”* (P23); *“I wanted to be a social worker in future. I feel sorry for the children (orphans due to HIV) and I decided to volunteer and with the limited knowledge I have I make a difference in their lives”* (P3). These comments indicate that caregivers loved working with people and loved to talk to, teach, share with and encourage them in order to make a difference in their lives. Furthermore, they were sympathetic towards the patients; hence they tried to work with them in order to bring about change.

#### **4.8. CHALLENGES OF PALLIATIVE CARE VOLUNTEER CAREGIVERS**

Volunteer caregivers experience many challenges while they provide care to their patients on a daily basis. This section highlights the issues that these caregivers faced while providing care to patients, such as workplace challenges, difficult patients, and personal and financial problems.

##### **4.8.1. Challenges in the workplace**

Volunteer caregivers often experience challenges in their organisations which cause an excess of stress in their lives. Participants in this study indicated various problems in the workplace, such as a shortage or lack of supplies, work-related problems and a heavy workload.

###### **4.8.1.1 Shortage or lack of supplies**

Most of the participants reported difficulty regarding the lack of basic equipment such as glucose measuring equipment, as many of their HIV patients also suffered from diabetes. In addition, they lacked TB test kits, masks, gloves and bandages. They indicated that they had few home-based care kits and these were incomplete. The participants explained the situation as follows: *“We have difficulties because resources are not enough, no gloves in the organisation so we end up wearing plastics to assist the patient”* (P1). Other volunteer caregivers said the following about risky behaviour due to lack of working material: *“No cotton wools and other material therefore we have to skip the patients that day because we cannot risk our lives”* (P20); *“It becomes so difficult sometimes because we have to ask for a*



*cloth to use as a bandage of which it is still risky” (P6).* It is clear that volunteer caregivers often found their work dangerous and unsafe due to a lack of much needed supplies. Many caregivers are reporting lack of necessary materials to do their job and this raises a serious concern about their well-being.

#### **4.8.1.2 Work-related problems**

Certain volunteer caregivers indicated that they encountered work-related issues such as problems with work policies, leave days and days off. They also indicated communication problems between the organisations and the volunteer caregivers. They reflected as follows: *“We are being neglected especially with our complaints. Nobody is taking us seriously when we ask about our day off and leave days” (P18); “We work long hours and get our incentives after a long period of time (‘dry season’ lasts for three months)” (P19).*

Volunteer caregivers also highlighted communication problems between the organisation staff and the caregivers. Some responded as follows in this regard: *“There is no good communication because we are sometimes called urgently while in the field and it disturbs our work for that day” (P2); “No feedback, no solution to our problems and it is so discouraging, I end up changing direction or not go to the patient as it is difficult to face them after disappointment” (P23).* It appears from these findings that there are difficulties over exploitation by managers, lack of transparency and poor relationships with volunteer caregivers. Some caregivers purposefully avoid seeing some of their patients because of being unable to give answers to their questions or to provide what they have promised.

#### **4.8.1.3. Heavy workloads**

Another challenge faced by volunteer caregivers in this study was heavy workloads. Participants indicated that while taking care of the patients, they needed to take care of their own children as well, which presented a considerable challenge to them. They also mentioned that the challenge became overwhelming at times, hindering the care that they should provide to their patients. Some commented as follows: *“I have to see ten patients per week and it is a problem as we have only one kit per pair, each caregiver has nine to ten patients and when you are two you add the number of patients together, it is time consuming” (P13); “When your partner is not around you have to work very hard to assist the patients for that day. It is even more difficult if you have bed ridden patients as you have to use all your energy and*

*more time to assist them” (P20); “It becomes difficult when families do not want to take the responsibility of caring for their sick patient as you have to do everything when you arrive and it’s too much work and too little time” (P4).*

It is evident that the multiple tasks the volunteer caregivers perform often resulted in them neglecting their own self-care with regard to nutrition, exercise, socialising and sleeping. This indicates that it is difficult for them to perform their duties effectively as they are always in a hurry to see other patients.

#### **4.8.2 Difficulty with patients**

Caring for people living with HIV often creates difficult relationships between patients and caregivers as the patients’ moods often fluctuate. Participants in this study mentioned difficult relationships such as rejection by patients, blame by patients and failure to adhere to treatment by patients.

##### **4.8.2.1 Rejection by patients**

A number of volunteer caregivers reported rejection by some of their patients who simply refused their assistance. Furthermore, the caregivers found some of their patients so problematic that they caused conflict between the caregivers and the managers. They frequently made false allegations. For instance, they complained to the management that the caregivers had not come to see them in months. Other patients refused the caregivers entrance to their houses when they felt better and stronger. Caregivers expressed their views as follows: *“Some chase us from their houses saying: ‘If you do not have the resources what are you coming to do here?’” (P7); “They refuse our assistance and when they are critical they need us and it is too late by then” (P20).* Another participant said, *“When they feel stronger and don’t want us anymore, they make false claims with the hope to cause conflict, so that we can stop seeing them” (P24).*

From the above responses, it appears that there are patients who are difficult and uncooperative. Some become arrogant and lazy in such a way that even when they were not overcritical, they did not try to help themselves. Others decide that they no longer need assistance and chase the caregivers away, only to call them back when they are feeling sick again.

#### **4.8.2.2 Blamed by patients**

Some volunteer caregivers reported being accused by patients of not doing their jobs. Caregivers often do not have the resources needed to help the patients who expected them to do more than they were capable of doing. They reflected as follows: *“They want me to inject and give them medication which I cannot do. When I explain to them that I have boundaries, a limited scope as a caregiver, I am not a nurse they blame me for not knowing what I am doing”* (P19); *“They blame us when they become sick that we did not take good care of them. They ask what we are doing in their households since they are not getting better”* (P1).

These comments indicate that patients sometimes displayed anger towards the caregivers by abusing them verbally and chasing them away. Some of these patients were never satisfied with anything given to them. They always complained and blamed the caregivers for not doing their jobs properly, especially when they are in pain.

#### **4.8.2.3 Failure to adhere to treatment by patients**

A number of the patients absolutely refused to take their medication, saying that they felt worse after taking their medicine (vomiting is often a side effect when they begin taking their ARVs). Others would postpone collecting their medication from the clinic, while some skipped their regular doses. Caregivers said the following: *“The male patients usually complain that the medication we provide is killing them and (they) decide to discontinue it”* (P12); *“Patients do not want to stand in queues for medication even when they can. They blame us when they become sick that we did not bring their medication on time”* (P2); *“They usually give an excuse that they forgot and when you make them to take them while you are there, they put the pill under the tongue and when you are gone they throw it under the bed. You will only recognise when the condition does not improve”* (P5); *“They lie to us, they would say they have taken their medication when you ask them and when you ask to see the medication the packet is still sealed, and when you ask they say the medication makes them feel worse”* (P24).

Failure of the patients to adhere to their treatment contributes significantly to the volunteer caregivers’ feeling of helplessness. Although ARV’s are available to their patients, the latter often default because they do not follow the instructions properly.

#### **4.8.2.4 Taking care of a patient's sick family members**

Another challenge that volunteer caregivers highlighted in this study was the misuse of their resources by having to take care for the patient's sick family members. There are situations when caregivers visit a patient and find that the other family members are also bedridden. Caregivers found it very difficult to take care of all the patients in one household at the same time. In such a case, they usually refer one of the sick family members to clinics, hospitals or hospices, with agreement from the family and the organisation's managers. Examples are: *"If there are two bedridden members in the family we refer one to a hospice"* (P21); *"When two members are sick in the family we usually refer one of them to places that can be of assistance with regard to improving their condition"* (P16). *"Sometimes we have to involve the social workers because when two family members are sick, when we separate them children also suffer, so the social workers help us by arranging for a temporary accommodation in the shelter until their parents are better"* (P2).

It makes it very difficult for caregivers when it is expected of them to take care of the Aids patient as well as some sick family members at the same time. Hence, they request other service providers to assist them in handling the situation.

#### **4.8.3 Personal challenges**

Volunteer caregivers working in the HIV and Aids field experience various personal problems due to the stressful nature of their work. Personal difficulties such as physical, psychological and emotional ones were mentioned by caregivers.

##### **4.8.3.1 Physical challenges**

The volunteer caregivers reported symptoms of poor physical health that were associated with care-related demands. They indicated experiencing physical problems such as exhaustion and fatigue, backaches, muscular aches, skin aches and headaches.

##### **(a) Exhaustion and fatigue**

The volunteer caregivers reported that they felt tired and weary most of the time after work, due to walking long distances and working with many patients. Some participants responded as follows: *"I am always tired when I get home, I am unable to assist my child with her*

*school work and when I do I feel drained” (P19); “I am unable to do the house chores when I knock off because of tiredness but I force myself to do so and I end up becoming more exhausted than ever” (P11); “When I sleep every day I feel so weary, so drained. It is even difficult to wake up in the morning but when I think of my patients I have to wake up” (P14).* It is clear that caregivers do not have enough time to rest as they have to work every day to assist their patients. Caregivers are always exhausted, which impedes the effectiveness of their service. It shows that the well-being of the caregivers is affected by the job they do as well as the conditions in which they work.

#### **(b) Muscular aches and backaches**

Volunteer caregivers indicated that they suffer from muscular aches and backaches due to lifting of bedridden patients while bathing and changing them every day. They reflected as follows in this regard: *“It will be much better if they send the younger caregivers to patient’s households that are far from the organisation as I always have muscular aches because of the distance we walk” (P20); “When the kit bag is complete it is too heavy and I end up feeling the pains on my shoulders and at the back when I sleep” (P10); “When my partner is absent from work I have to take care of all our patients. I usually have a backache because of lifting the patients alone especially where families are not interested” (P24).* It is evident from the findings above that the caregivers use more energy to assist their patients when the patients are unable to do things for themselves. Hence, they end up experiencing the challenges described above.

#### **(c) Skin aches and headaches**

Some participants also reported that they have skin problems and also experience constant headaches. This is what they said: *“We walk around, long distances in the sun, you develop skin problems and sun block is expensive. I cannot afford to buy it” (P3); “When it is too hot I develop a rash on my skin and an umbrella becomes heavy for me to carry it every day” (P22); “I have severe headache especially when it is hot, then I have to sit down and drink water” (P13), “I always have a headache especially in the morning and evening. When I go to the clinic they give me tablets but they are not helping at all” (P5).* It appears that caregivers often experience skin aches and headaches when it is hot as they walk in the sun without protection. It is evident that caregivers do suffer from physical challenges while

trying to do their job of care giving. It is therefore important for the organisations to acknowledge this issue and act accordingly to assist them.

#### **4.8.3.2 Psychological and emotional challenges**

Caregiving was experienced as being psychologically and emotionally burdensome by the participants. In this regard, they experienced different emotions such as feelings of frustration, fear of infection, anger, loss due to death and tension about cultural beliefs.

##### **(a) Frustration**

Volunteer caregivers working in the HIV and Aids field experience various frustrations due to the nature of their work. Therefore, under the subject of “frustration”, they identified certain sub-themes such as frustration due to limited clinical training, frustration with the patients, frustration with the nursing personnel and feelings of anxiety and distress, all of which are discussed below.

- **Frustration due to limited clinical training**

Some volunteer caregivers expressed frustration in dealing with the complex clinical aspects of the health of their patients such as septic wounds, which included bedsores. Wound care does not form part of their training in home-based care and this makes it hard for them to provide quality care to the patient. They commented as follows: *“Some of our patients’ conditions traumatise us as they are new to us; we were only trained for three weeks on the basics of caregiving”* (P2). *“We never experienced that before for example a bed sore, it scared the hell out of me, it really traumatised me”*(P12). *“I heard people talking about bed sores but never saw it. It was frustrating as I did not know where to start but my partner came to the rescue”* (P17);

It is evident from the findings above that the volunteer caregivers felt frustrated because they did not receive enough training to deal with the clinical aspects of their work. However more intensive training about the clinical aspects of caregiving could equip them to provide a better service and, as they mentioned during the interviews, auxiliary nursing can assist in dealing with some of the clinical problems they encounter.

- **Frustration with the patients**

Caregivers expressed their frustrations with patients who do not want to cooperate and ignore the instructions they give when they do their home visits. Some responded as follows: *“Some patients become short tempered, become aggressive. They do not open their doors for us and when they are in a dying stage they refuse to see us and want to be assisted by a nursing sister who is not always available. By that time it is too late and there is nothing we can do and it is so disturbing”* (P22). *“Those who do not take their treatment they make us feel like failures when their wounds become septic, they make us feel we have failed them and it is so frustrating when you see them deteriorating”* (P11).

It is evident that caregivers felt very frustrated when they see their patients suffering from pain over which they had no control. Patients need to be encouraged to adhere to their medication in order to reduce the burden of care from the volunteer caregivers.

- **Frustration with the Nursing personnel**

Volunteer caregivers were also frustrated with their colleagues who misused them and expected too much from them. *“Sometimes it is so disturbing when nursing sisters want us to do the job while they run away from it”* (P6). *“She was supposed to assist me but she remained in a car while I do the job alone, she must assist me as she needs to report to the clinic about the patient’s condition”* (P4). It is clear from the finding above that there is not a good working relationship between the volunteer caregivers and some of the nursing sisters from the clinics. The problem needs to be addressed so that the well-being of the patients is not compromised as a result.

- **Feelings of anxiety and distress**

Feelings of anxiety and distress were experienced by the participants when they realised that the condition of the patient was deteriorating. They responded as follows: *“Sometimes you see your patients give up, you try to help them but they have already given up and we cannot fight for them, it kills me”* (P21); *“It is painful to see your patient suffer in pain and there is nothing you can do about it. You go to the organisation and there are no resources, you go to the clinic no medication to help”* (P4); *“It is so stressful when patients deteriorate in front of you. I put myself in their shoes and feel that I might die like that”* (P16); *“They just feel pain everywhere and this makes me feel helpless and I cannot sleep waiting for the next day to see them”* (P10);

A major source of anxiety and distress for some volunteer caregivers is the fact that many of their patients live in poverty, for example in shacks with no windows. Others live in a one-roomed shack with a bed and everything is done in that one-roomed house. They reflected as follows in this regard: *“When the patient gets very sick it feels bad as he or she stays alone in the house. When the weekend arrives it becomes painful as you will only see him/her on Monday. I cry all the time but there is nothing I can do as I have my children to look after”* (P5); *“When you have to attend a workshop it’s a problem because you do not concentrate if you have a very sick patient. Sometimes when you go for a visit you are told we will bury him/her next week or we buried him/her on Saturday”* (P23). Anxiety and distress cause a lot of strain to the volunteer caregivers as their minds are always on their patients. They wait anxiously to see them on their next visit with the hope of finding them alive, and when they do not find them (alive), it increases their stress.

#### **(b) Fear of infection**

Fear of contagion is one of the major concerns among caregivers working in the field of HIV and Aids. Volunteer caregivers mentioned that they sometimes notice that there is no change in the patient’s condition and when they monitor them, they realise that patients do not take their medication; this puts them, the volunteer caregivers, at risk of being infected, especially with TB. They remarked as follows: *“When patients do not take their treatment (especially for TB), it is risky to us as caregivers because we can be infected easily. They also default and die earlier than they should”* (P3); *“As we do not have resources sometimes our lives are in danger; we attend to patients without masks and gloves sometimes. We enter the patient’s houses and open the windows without masks on and if the patient is suffering from TB and is not taking medication we can catch TB easily”* (P11). Some participants complained that *“It is difficult to follow precautions sometimes because others do not want us to enter their homes with masks on, and when we give them masks to use while we are not there they throw them away”* (P8). It is evident that despite the knowledge that caregivers have about HIV and TB transmission, they still experience fear of contagion because precautionary measures are not always followed due to a lack or shortage of resources which compromises the quality of care that the patients require.



### **(c) Anger**

Anger is often experienced by caregivers when their patients are not cooperative and eventually become very sick. Most participants revealed that they struggled with their emotions when it came to dealing with losing a patient. These emotions include a high level of anger and a feeling that they could have done more for the patients even when they are aware that their patients are deteriorating. They reflected as follows: *“The patients can lie to you, you ask them if they’ve taken their medication they say yes, but when time goes on you see them deteriorating. When you take them to the clinic they say the patient has defaulted, it makes me angry as I feel I am fighting a losing battle.”* (P9); *“It is so irritating to try to assist the patient and realise that there is nothing you can do, you are aware that there is no solution to the problem”* (P12) *“Losing patients due to ignorance or carelessly refusing to follow instructions makes me mad, they will say I will be resting when I’m dead forgetting that they have children to take care of”* (P5). It is clear that caregivers often experience feelings of anger when their patients refuse to cooperate. They also feel helpless and frustrated when they realise that the situation of their patients is beyond their control.

### **(d) Loss due to death**

Participants expressed difficulty with caring for patients whom they knew might not fully recover or be cured of their diseases. They struggled to accept their patients’ condition. This often caused certain participants to feel stressed, although others mentioned that they accepted the condition of their patients. They believed that ARV treatment might assist the patient to live longer. However when the patient they cared for died, they felt more stressed and could not cope. They commented as follows: *“Patients usually prescribe themselves treatment or medication and we end up losing them on the way. One day I went to see her and found that she had died. This never sat well with me”* (P7); *“I treated the patient for a short period of time and felt strongly that with ARV’s she will survive but I ended up losing her, it was so difficult to accept”* (P24); *“Patients usually prescribe themselves treatment or medication especially when they feel the pains, you will hear them groaning in pains and some scream when you try to assist them. When they die you feel they are relieved but it is so painful”* (P18). Another one said: *“Elderly family members refuse to go to old age home when the patient die. After death of the patient the person remain alone in the house and we will only be there for some time as we care for sick people not the elderly”* (P1). It is clear from the findings above that although some caregivers felt stressed and could not cope when

a patient died; others felt that the patient was relieved of pain. All these feelings depended on various factors such as the level of attachment between the caregivers and the patient. When the caregiver becomes attached to the patient, they experience more pain when the patients pass away.

#### **(e) Tension about cultural beliefs**

The volunteer caregivers indicated that some of their patients visit both traditional healers and formal health care providers, such as the clinic. Many patients have a strong belief in traditional medication and often request the caregivers to administer the traditional medicines to them. The latter reflected as follows: *“It is difficult to change the patient’s attitudes, some are sick but still hold onto their culture even when they are dying”* (P8); *“They will ask you to administer the traditional medicine and when you refuse and give reasons they would say: ‘so you want to control me in my own house?’(P2); “They end up being critical and some default on their ARVs or TB medicines”* (P11); *“Cultural beliefs, they want you to administer traditional medicine of which you can’t because you are not trained to use both treatments, and they die due to ignorance”* (P4). Cultural sensitivity is necessary in order to provide quality and effective home-based care to patients with HIV and Aids and their families. It is also evident that culture plays an important role in home-based care because the patient’s cultural practices will be a priority in their own homes. Therefore, caregivers should understand different cultures in the communities where they work in order to function effectively. They should, however, also learn skills regarding how to cope with patients who insist on taking traditional medication.

### **4.8.4 Financial challenges**

Finances are another challenge that volunteer caregivers have to face. Financial issues such as poor funding and not enough money for food are some of the issues raised by them.

#### **4.8.4.1 Insufficient funding**

The most common problem and stressor reported by almost all the participants in the study was a lack of funds for them and their patients. The volunteer caregivers in this study indicated that they received certain payments in the form of stipends. However, these were not enough to sustain them for the whole month. Lack of donations and sponsors as well as

insufficient funding by organisations led to a lack of financial incentives (stipends) for the caregivers. Volunteer caregivers had to wait for a long time to receive their stipends due to inconsistencies. Some participants reflected as follows: *“Sometimes patients do not have money to go to the clinic and we also do not have money to assist them”* (P16); *“We always have a dry season (three months without incentives). If we had money we were going to transport the patients to the clinic so that they should not default”* (P10); *“Patients’ children do not respect us, they also do not want to assist because they think we are getting paid to assist their parent. Sometimes we suffer because of our love and patience”* (P2); *“It is a problem when you have to give the patient medication and find that there is nothing to eat, and I also do not have money to buy some bread or something for him or her”* (P22). The financial impact of HIV and Aids can never be underestimated because patients need money to buy their necessities and caregivers also need funds to sustain themselves. The issue of financial hardship is another serious issue among those challenges that caregivers face while doing their job.

#### **4.8.4.2 Inadequate nutrition**

A great cause of concern for the volunteer caregivers was the lack of adequate and proper nutrition for their patients, mainly because patients did not have enough money to buy food. Although there has been an improvement in the distribution of ARVs, these are sometimes difficult to administer because patients cannot take medication on an empty stomach. Some participants remarked as follows: *“Many of our patients do not have nutritious food and we are also not able to provide them with some and that makes our job more difficult”* (P7); *“I visited my patient one day and I found her washing stale chicken portions from the dumping site nearby. Her husband does not have any income and they have kids to take care of. It was painful for me as I did not have anything to offer when I stop her”* (P24). Another participant said that, *“Food parcels from the church are not enough and some community members do not support care giving. Most of our local leaders only get involved when we are holding funerals”* (P19). It appears from the findings above that, because of their own poverty, the caregivers acknowledged they were not able to provide what the client needed. This was also exacerbated by a lack of support from relatives, friends or community systems.

## **4.9 COPING MECHANISMS OF PALLIATIVE CARE VOLUNTEER CAREGIVERS**

This section highlights the caregivers' ways of coping with the challenges that they face while doing their job. Research has discovered a link between the stressors HIV and Aids caregivers experience and the coping strategies they use. The researcher was therefore interested in exploring the different coping mechanisms used by volunteer caregivers. As mentioned, the participants employed a number of strategies such as avoiding of the problem during times of stress, trying to solve the problem or seeking help and support.

### **4.9.1 Avoidance of the problem**

As mentioned before (Section 4.5 refers), almost 46% of the volunteer caregivers coped with their stress by avoiding the problem. When they realise that they are out of options, most caregivers said that they simply try to forget about their difficult situation and accept it the way it is. They reflected as follows: *"Sometimes it is not easy to handle the problems, so I just try by all means to forget about it and listen to music when I get home"* (P9); *"If I see that there is nothing I can do, I just ignore the situation and only continue doing what I can"* (P11); *"Some of the problems are beyond my control so I just accept the situation and move on"* (P22); *"Sometimes I scream off to others, and my friends would say 'you are no longer in the field now come back'. Then I would try to distract myself by watching TV"* (P8); *"When the situation is difficult I try to block it out by ignoring it and when I can't forget I start crying"* (P1). It is evident from the quotes above that when volunteer caregivers fail to handle the stress they try to avoid the situation, ignoring it in the hope that it will go away.

As said before, it is of great concern that so many volunteer caregivers use avoidance as their coping mechanism. Avoiding the problem is often a less effective coping strategy because it does not provide a long-term solution. However, it may be a suitable choice if the source of stress is outside of the person's control.

### **4.9.2 Trying to solve the problem**

Almost thirty percent of the volunteer caregivers (Section 4.5) used problem solving to try and reduce the cause of their stressors. They reflected as follows in this regard: *"I usually have sleepless nights if I do not find a solution to the problems I have. Then I make sure I find something even if it's a short term solution"* (P10); *"I try to solve the problem by talking*

*about it with the patient's family, also trying to understand the situation" (P4); "I usually talk about the situation so that I can get ideas on how to go about it," (P14); "Always when I encounter a problem I try to evaluate options for dealing with it. I also pray and place the problem in God's hands" (P22); "Talking about the situation and try to find solutions minimise the feelings of stress and when I keep things to myself I become sick" (P2).*

Although the use of avoidance of the problem was the dominant strategy used, it is clear that many volunteer caregivers also utilised problem solving as a coping strategy. Prayer was very often used by caregivers to cope with their situation. Although prayer is not strictly a problem solving mechanism, it was used by caregivers as an attempt to influence solutions to their problems. Some also used prayer to change their perceptions of their difficult situations (for example, "placing the problem in God's hands").

#### **4.9.3 Seeking help and support**

A quarter of the volunteer caregivers (Section 4.5) coped with their problems by asking for help and support from others. They responded as follows: *"I share my patient's problems with the nursing sisters at the clinic for them to assist me" (P24); "I ask my fellow caregivers who were with the organisation for longer on how they handled the situation before" (P5); "Even though I ask my friends I am working with and nurses it is still not enough as the patients respond differently to situations" (P18). Some said: "I always report the problem to the managers and the nurses when there is a problem as some need the organisation and not an individual and I feel relieved after that as the burden is no longer mine" (P20); "Sometimes I talk to my husband at home as I need somebody to listen to me and assist with ideas" (P3). Apart from seeking social support, many caregivers obtain support through prayer, for example: "I always pray to God for guidance and strength to handle the situation, and I believe that He will assist me, and I become better afterwards" (P11).*

It is evident that volunteer caregivers invariably need shoulders to cry on; they need people to give them support and assistance when situations are difficult. Therefore, organisations should make sure that they provide such support to assist their caregivers.

#### **4.9.4 Active strategies**

When caregivers asked about what they did to relax, they mentioned active strategies such as taking a walk, listening to music, playing with the kids and sleeping. Some said: *“I usually take a walk when I go home instead of using a taxi so that I can clear my head and forget about the situation before I arrive home”* (P6), *“I like playing with my kids when I am not too busy to forget about the situation”* (P9); *“I prefer to be alone relax and listen to music, it feels so good”* (P21); *“When I arrive home I take a nap when the kids are still playing before I can start preparing supper”* (P15).

#### **4.9.5 Positive experiences and emotions**

Although the Broaden and Build theory of Johnson et al. (2010) was not directly tested in this study, caregivers shared many positive experiences and emotions that they derived from caregiving, with the researcher. They indicated that these positive emotions are what kept them going in a very difficult situation. Although the sample was too small to make any significant deductions, there was a tendency for caregivers who experienced their caregiving role as positive to have lower scores on the Perceived Stress Scale, which probably also mean that they have better coping mechanisms.

In conclusion, it is clear that volunteer caregivers usually used both emotion-focused coping and problem-focused coping strategies. They also made use of coping strategies that were associated with less distress and better emotional adjustment. To see their work in a positive light and to get enjoyment from their work also seemed to help them to cope better. None of the volunteer caregivers indicated that they used drugs or alcohol to solve the issues encountered.

#### **4.10 NEEDS, CHANGES AND AVAILABLE RESOURCES**

In order to explore the needs of palliative care volunteer caregivers in their organisations, the participants were asked what they would like to change in their organisation that could have a direct effect on their everyday lives. They raised many issues that needed careful consideration. It appeared that some had lost faith in the functioning of the organisation, and they remarked as follows: *“I no longer care about what is happening in this organisation, or what is changing, I’m just concentrating on myself and what I can do and cannot do”* (P6); *“I*

*don't see myself growing in this organisation, I have been here for long, but anyway I am trying by all means to learn everything. I do caregiving, gardening, support group facilitator" (P4); "I just want to move on but cannot just quit. I need something to do or a job or something else not just staying at home doing nothing" (P20).*

The needs and changes that the participants emphasised are discussed below.

#### **4.10.1 Time and appreciation**

Some participants indicated that they were not given enough time to rest since they finished late every day. Even though they worked hard, the organisation did not appreciate them or acknowledge the good work that they did for the patients. A need that was expressed by most volunteer caregivers was the need to gain more time for themselves in the form of shorter workdays, a day off and leave days. Some participants expressed the following views: *"Knock off time should be changed; we knock off late if we can knock off earlier it would be good as we have families to take care also" (P15); "If we can knock off earlier we will be able to take good care of ourselves because on weekends we are always busy too" (P9); "It would be good for us to check the patients only and not go to the clinic for patient's medication as that takes most of our time" (P22); "No appreciation in this organisation, we need to be appreciated for the good work that we do, we need to be given feedback on whether we are doing well or not" (P2).*

It is clear that volunteer caregivers need enough time to rest and do their own family responsibilities. Although caregivers were appreciated by some of their patients and community members, they felt that it would be good for their organisations to appreciate them as well. They understood that an important reward for volunteering was the love and appreciation shown by people receiving their services.

#### **4.10.2 Resources or material**

Volunteer caregivers expressed their frustration with the shortages of resources and material to do their work. They often did not have enough home-based care kits to do their work properly. Such a kit is a bag that has supplies that caregivers use when they visit the patient's home. The kit contains items such as linen savers, crepe bandages, pull-up nappies, mouth wash, hand wash, zinc oxide lotion, painkillers, cotton wool and examination gloves.

Caregivers use examination gloves to protect themselves from touching the wounds with their bare hands when they have a bedridden patient with wounds. However, those resources are not always available and most of the time the kits are incomplete. They responded as follows in this regard: *“We work in pairs and only one kit available and that makes our job more difficult as we have to see a large number of patients per day”* (P4); *“I feel that material should be available always and kits should be complete”* (P8); *“Shortage of medical supplies at the clinic also makes our job burdensome because patients need medication of which we do not have”* (P20). The local clinics sometimes assist them with the supplies but it is difficult when both the clinic and the organisations do not have the required supplies in stock. *“We need to have our own resources to function effectively without any fear of infection”* (P1).

The lack of resources for volunteer caregivers to do their work properly is a serious problem which demotivates them in doing their work. It needs to be taken up with the appropriate authorities to make sure that caregivers are supported in their work by providing the necessary resources.

#### **4.10.3 Transport**

The need for proper transport for volunteer caregivers to do their work properly was also expressed. The organisations have cars that sometimes drop caregivers off to visit their patients, but in one organisation, the car is often unavailable due to the lack of petrol. Most of the time participants reported walking long distances to visit their patients; thereafter they have to walk back to their organisations to “clock out”; a process that they found extremely strenuous. Many caregivers therefore reported that they needed better transport to visit their patients on a daily basis. They remarked as follows: *“If we can get transport because we walk long distances and we spend a lot of time on the road”* (P6); *“If the organisation can buy bicycles for us it can also help because walking a long distance with a heavy kit bag is strenuous”* (P12); *“Our transport is small (Toyota Venture), if we can get a bigger transport (e.g. Toyota Quantum or mini bus) it will assist a lot”* (P23).

It is obvious that transport problems had a bearing on the job of the caregivers as their place of work was far from the patients’ households. Therefore, by the time they got to the patients’ houses, they were too tired to provide a satisfactory service to their patients. They had to do their work in a hurry trying to cover all the patients they should assist for that day.



#### **4.10.4 Stipends and incentives**

All the participants felt that they were not earning enough. They could not afford to enrol for courses on their own to empower themselves with skills. They had to depend on the availability of what the organisations could offer them. Volunteer caregivers received a stipend of R1000 per month yet sometimes, as indicated, they were obliged to wait for three months before they could get their stipends. They aired their views as follows: *“There should be no dry season (three months waiting period for incentives). Although it’s little if we get it every month it will assist us”* (P3); *“There should be fairness in everything the organisation do also in terms of stipends and incentives, they should pay for all us for trainings as we are all doing the same job”* (P19); *“The organisations need to do fundraisings – because when there is no money we drag ourselves for two months and it becomes stressful”* (P14).

Most NGOs (such as the organisations the volunteer caregivers in this study worked for) are dependent on donations and support from other organisations as well as support from some of the government departments. Organisations are thus pressed for money themselves, but it should be kept in mind that caregivers are taking great responsibility in providing care for people living with Aids. Given the emotionally strenuous conditions under which they work, caregivers should be provided with reasonable financial incentives in order to improve their morale.

#### **4.10.5 Workshops and training**

All caregivers who participated in the study were required to undergo training (Section 4.3 refers). The research participants felt that there were minimal opportunities for growth, despite their training and years of service. The training they attended did not equip them for some of the clinical challenges they encountered. They suggested the following: *“We need to be taught or trained about teamwork; lack of unity discourages a person”* (P2); *“This cannot be a lifetime job in the absence of training to empower us. I need to study further and improve my skills”* (P5). *“All of us should be trained for 69 days (Home-based care training) as there are some who have been trained for one week but we do the same job”* (P24).

It is evident that caregivers would like to develop their skills to become auxiliary nurses, if possible, and to maximise their chances of accessing other job opportunities. Organisations should prioritise training if they want to keep their volunteer caregivers.

#### **4.10.6 Communication skills**

There is clearly a lack of communication between senior staff members and the volunteer caregivers, causing a lot of confusion and misunderstanding. The caregivers reported that they were not listened to and were often accused of not doing their duty effectively, but felt that these accusations are not true. They further felt that they were not given a chance to explain their opinions during such confrontations. They end up feeling vulnerable and disrespected by their managers. They further expressed sadness because they were often not given the opportunity to raise their views and concerns. They reported: *“Even if I can say something nobody will accept the idea; we are not recognised”* (P22); *“The managers do not take long to attend to our problems when we present them, we are not listened to”* (P7). Other participants said, *“We need to have weekly plans, a programme to follow as we are sometimes called while on duty that there is a meeting, visitors and that disrupts our work”* (P11); *“Management should be transparent to us, we feel ignored and undermined always running around like headless chickens”* (P1).

Communication is clearly a problem and volunteer caregivers need training on how to address communication problems. Managers should be made aware of this issue that needs to be taken into consideration.

#### **4.10.7 Counselling and debriefing**

Participants reported that they encountered many difficulties that came with caring for people living with HIV while they also experienced their own personal and social problems after work. They reported that they needed counselling and debriefing services every three months. There was clearly a need among volunteer caregivers for sufficient support in their organisations. Some reflected as follows: *“We need to have counsellors who can assist us with our social problems”* (P13); *“As we knock off earlier on Friday sometime, it would be good to do some debriefing sessions. We need somebody to intervene and give us counselling”* (P9); *“It will be nice to have motivational speakers to motivate and encourage us”* (P21); *“I think to be in a different environment for a day can help a lot, maybe once or twice a month”* (P6).

As was reported in Section 4.3, only six of the twenty four volunteers (27%) said that they belonged to support groups. Managers should promote the health of caregivers by providing

support to them, such as counselling, support groups, debriefing and training. The comment from one caregiver that they are even prepared to attend counselling or debriefing sessions on a Friday after work indicates their dire need for some form of support.

#### **4.11 CONCLUSION**

This chapter presented the results of the two measuring instruments (the PSS and the CSI). It gave a detailed account of the experiences of a palliative care volunteer caregiver's role, which encompasses the rewarding experiences as well as difficult ones that require intervention from the organisations. The findings also drew attention to the challenges that palliative care volunteer caregivers face on a daily basis as they provide support to people living with HIV and Aids. The discussion includes the coping mechanisms adopted by the volunteer caregivers for dealing with the emotional and physical strain of the job. Their needs were emphasised to assist the organisations to improve their services. The findings of this study are discussed in the next chapter and recommendations are made based on the findings of the study. These recommendations will be forwarded to palliative care volunteer caregivers, organisations and the government departments involved with home-based care.

## **CHAPTER 5**

### **DISCUSSION, CONCLUSIONS AND RECOMMENDATIONS**

#### **5.1 INTRODUCTION**

Although there have been remarkable results from antiretroviral therapy since the 2005 ARV-rollout in South Africa, people with HIV-infection and Aids continue to need care and support. Volunteer (as well as professional) caregivers often take on the responsibilities of caring for patients with Aids in their homes and communities (Uren & Graham, 2012). The life of being a volunteer caregiver in the Aids field in Africa is not an easy one and the work they do often goes unnoticed and unappreciated (Maes & Shifferaw, 2011). The current study attempted to shed some light on why volunteer caregivers, who provide home-based care in Soshanguve, in South Africa, do what they do and how they experience their role. The psychosocial challenges experienced by these caregivers were explored as well as the strategies they use to deal with the daily challenges they experience. Finally, the caregivers' needs as well as the support available to assist them in coping with their work were explored and are discussed below.

#### **5.2 REASONS WHY VOLUNTEER CAREGIVERS OFFER TO HELP PEOPLE WITH AIDS**

Caregivers are willing to volunteer their services to people living with Aids for various reasons. Volunteer caregivers often have unique and very personal reasons for volunteering their services. Akintola (2010b) identified the following reasons why caregivers volunteered their services: a need for competence, self-growth, self-esteem, autonomy and reciprocity, social connections, a perceived community need and being rewarded in some way. UNAIDS (2010) highlighted other reasons or motivations for care-taking: compassion, self-interest, a sense of religious duty, the need to control the disease and the hope for a paid income and incentives offered to volunteer programmes.

The reasons identified in the literature reflect the motivations provided by the volunteer caregivers in the current study. Many volunteer caregivers volunteered their services with the desire to serve their communities by promoting better health practices amongst people (also see Kang'ethe, 2010a). They viewed their job as meaningful and important because they were

interested in helping others. Others continued to volunteer with the desire to be recognised and accepted by their patients and communities. When the volunteer caregivers perceived that the work that they were undertaking was creating a positive impact in the lives of their patients and community, they were encouraged to work even harder. Uren and Graham, (2012) in their study also found that the recognition of positive experience increased the caregivers' feeling of pride in their ability to meet challenges and improved their sense of self-worth.

Apart from the desire to help others, some volunteer caregivers were drawn to volunteering their services because they themselves were exposed to trauma and/or were HIV positive themselves. Many told stories of how they were motivated by their own personal experiences, such as caring for their relatives, family members and friends who have Aids or who died of Aids. Although there was no specific question in the study that asked about their HIV status, some volunteer caregivers revealed their HIV status and said that they offered their services because they were HIV infected themselves. They experience the challenges of HIV infection first-hand, and they want to empower themselves with knowledge and information to assist themselves in future. Volunteer caregivers who are HIV positive themselves might in future struggle to continue with the caregiving responsibilities due to issues relevant to their own condition (Ama & Deloilewe, 2011). Therefore, it is important for them to care for themselves and join support groups in order to cope effectively with their stressors. They need individual therapy or support groups to deal with the depression, hopelessness and anxiety surrounding the unpredictability of disease progression (Maes & Shifferaw, 2011).

Another source of attraction in doing volunteer work was acquiring experience in the hope of securing permanent employment in future since some of the caregivers were living in poverty stricken communities. Akintola (2010b) also found that many volunteer caregivers are themselves impoverished and that the organisations they work for are also financially challenged. Due to their lack of income and the poor opportunities for employment and training within the South African context, volunteer caregivers often hope that volunteering will lead to remuneration that will enable them to improve their lives. Some also volunteered to learn particular skills or to learn about an organisation with the hope of exploring job opportunities or of being introduced to a potential career contact. Although volunteer caregivers in this study were motivated by the need to improve their abilities and to secure permanent employment, many found it difficult to achieve their goals due to the limited

growth opportunities to which they were exposed in their respective organisations. However, they were always trying to improve their skills and knowledge about HIV and Aids as well as other health issues.

Some volunteer caregivers said that they were motivated or inspired by others to volunteer their services. Some volunteered for a particular event because their friends were doing so. Others volunteered because their family or a social group expect them to do so. Therefore, they believed that volunteering fulfilled their need to behave in a socially desirable way (also see Stunkel & Grady, 2011). Since people volunteer to satisfy personal needs, social needs and specific goals, those who are inspired by others may pose a problem for the organisations. Once they have fulfilled the reason for their motivation, the volunteer caregivers are likely to become inactive and even drop out of the organisation. Although organisations recruit and place individuals in appropriate activities, they must also strive to retain them in order to reduce high turnover rates and keep volunteers for longer periods (Maes, 2012). Organisations should properly screen and select volunteer caregivers to ensure that they volunteer for the right reasons.

Volunteer caregivers are often motivated to offer care to others to escape or avoid negative feelings (Maes & Shifferaw, 2011). Some of the volunteers who participated in the current study volunteered to relieve themselves from their feelings of guilt, whereas others experienced volunteering as psychosocially therapeutic because it allowed them to be socially active and effective in their lives. It further provided a relief or an escape from the negative feelings about themselves (Ama & Deloilwe, 2011). Volunteer caregivers who were motivated by guilt felt that they had failed to help or care for family members and friends who had died of the disease, and they blamed themselves for their neglect. They often felt remorse about the fact that they should have assisted with the physical care of the patient. They also felt guilty because they did not search for more information to assist the patient. Moreover, they were unable to forgive themselves. They therefore elected to work with sick people to ease their own consciences. Volunteer caregivers believed that by helping somebody else they would feel positive through being appreciated and being proud of having done something worthwhile which would aid their own healing. However, in reality the situation often becomes difficult, leading to volunteer caregivers feeling helpless and stressed, a situation not always recognised by the organisations for which they work.

Volunteer caregivers are largely inspired by community appreciation and moral duty. Hence they acknowledged that people living with HIV and Aids need their support. They also believe that they can make a difference in their patient's lives. The findings concur with the study done by Glenton et al. (2010) whose findings revealed that people are primarily motivated by a need for social respect and moral obligation. Although volunteer caregivers who participated in the current study were willing to develop awareness and contribute to the strengthening of their communities, they also knew that they are not able to do that on their own. They therefore joined organisations for the opportunity to do volunteer work and to make a difference.

Some caregivers volunteered because they knew of a friend or family member infected by HIV and were sympathetic towards them. They therefore worked with a clear objective in mind, namely, to make a difference in those people's lives as well as to be able to make a difference in their communities. Because they were HIV positive themselves, some caregivers felt more empathy for other infected individuals. For some caregivers, this was a reciprocal relationship because they in turn received information and assistance from their patients who were in the same situation. They further believed that if people in the community observed other HIV-infected individuals who are living positively, that might inspire them and give them hope to live longer too. These results relate to findings from Kang'ethe's (2010b) study, which found that many volunteer caregivers were rendering their services because they were also HIV positive and want to make a difference.

It would be conducive for the organisations to understand the different motivations that their volunteer caregivers seek to fulfil, since different individuals involved in the same organisation may be attempting to satisfy different motives. Managers should identify these needs and match volunteer caregivers with tasks that will fulfil those motivations in order to retain them. However, managers should also be aware that personal motivations might in some cases hinder the helping relationship and that the reasons for volunteering might be more selfish than altruistic. Steps should then be taken to re-train volunteers, to offer counselling or to re-allocate them to other patients where they will not do any harm.

### **5.3 THE CAREGIVING ROLE AS A POSITIVE EXPERIENCE**

Although caregiving in the Aids field presents many challenges, there are many fulfilling and satisfying aspects highlighted by volunteer caregivers in the current study. Many found their

work with patients and their family members to be very rewarding. They emphasised that there were families who were very understanding and gave their full support to their patients as was also found by Asuquo, Etowa and Adejumo (2013). This improved the quality of the relationships between the volunteer caregivers and the people receiving their services. The supportive families became used to and felt comfortable about having a patient around and wanted to know more about providing assistance to the sickly family member.

The majority of the volunteer caregivers felt a sense of personal accomplishment when their patients recovered from their sicknesses (Akintola, 2010a). Witnessing their bedridden patients recovering and fighting the disease caused them to feel fulfilled. It encouraged them to remain in the Aids field because they felt that they had personally achieved certain goals in their lives. Some of the patients also felt comfortable with the caregivers and shared their feelings and thoughts with them. Hence, volunteer caregivers became more attached to some of the family members and the patients, as they made their jobs easier.

According to the Broaden and Build theory of Johnson et al. (2010) positive emotions such as enjoyment of work, interest and contentment are able to facilitate the development of skills, networks, resources and capabilities, which in turn promote well-being and fulfilment. Cohn et al. (2009) further believe that positive emotions broaden one's awareness and also develop capacities that can function to build lasting resources to help caregivers cope with their challenges. Volunteer caregivers should therefore always be encouraged to actively think and talk about the positive feelings and experiences they derive from taking care of sick people.

## **5.4 CHALLENGES ENCOUNTERED BY VOLUNTEER CAREGIVERS**

Although most of the volunteer caregivers who participated in the current study enjoyed their caregiving roles, they had some negative experiences and were faced with many challenges which made their working and personal lives difficult. Although the Perceived Stress Scale indicated that caregivers experienced mild and not severe stress, they encountered many difficulties and challenges which might lead to stress and burnout if not taken care of.

### **5.4.1 Organisational and job-related problems**

Caregivers in the Aids field often leave their jobs because of job stress, burnout and lack of proper workplace support (Cox et al., 2010). The working environment of the volunteer



caregivers, who participated in the study, was in general conducive to providing good care. However, various problems of an organisational and job-related nature remained.

The volunteer caregivers were for example unhappy with the disparity in both the nature of their training (formal versus informal) as well as its duration (three weeks to 12 months). Though the majority of the volunteer caregivers received formal training, some had received informal training, mostly in the form of in-house training at the organisations where they worked. Some caregivers felt that they are at a disadvantage due to this disparity in training. In particular, it is of great concern that not all the volunteer caregivers were trained in home-based care, which is the foundation of their day-to-day work. Research done by Kang'ethe (2011) also commented on the disparity in training of volunteer caregivers working in the Aids field and the problems this creates for caregivers and patients alike. This disparity in training is unacceptable and can even be harmful to patients. The training often does not include some of the clinical aspects that caregivers are required to perform in the field. This was found to cause role conflicts among volunteer caregivers who were not able to offer equal or adequate services. Caregivers were sometimes required to perform roles that required nursing or clinical skills for which they were not trained. Coetzee et al. (2011) also mentioned role conflicts as well as the lack of skills due to insufficient training in their findings.

The number of patients for whom volunteer caregivers are responsible is another problem that can make caregiving strenuous for caregivers (Akintola et al., 2013). Some who participated in the study cared for more than ten patients and this needs attention by the organisations since too much work can affect their ability to provide quality care to their patients. Caring for too many patients can lead to irregular visits and sometimes to ceasing to visit some of the less ill patients while prioritising the bedridden ones. An over-demanding challenge may also lead to burnout, to volunteer caregivers dropping out, ultimately leaving the organisation with the problem of recruiting and training new volunteers.

The length of time that volunteer caregivers had worked for the respective organisations (from one to ten years) with minimal opportunities for growth and promotion was a serious problem for the volunteer caregivers. Some volunteers revealed that they “were growing old” in the organisation and that they are no longer physically strong enough to endure the demands of caregiving. It is clear that working in an organisation for a long period of time caused its own kind of stress, which could be overcome if the managers provide volunteers

with activities that match their motivations and satisfy their needs and goals (Ogunmefun, Gilbert & Schatz, 2011). Volunteer caregivers who are motivated and whose needs and expectations are fulfilled by their service will receive more satisfaction from their work and they may therefore continue longer in their service; however, as discussed above, those who are not satisfied are likely to drop out, leaving the organisations with the challenge of recruiting new volunteers.

Penn, Watermeyer and Evans (2011) found that a breakdown in communication between the caregivers and their managers was another problem encountered by caregivers in the HIV and Aids field. In the current study, it became apparent there was invariably confusion and misunderstanding about how volunteer caregivers should work in their organisations. Their day-to-day functioning was, for example, often disrupted when they were suddenly withdrawn from their duties - without prior warning - when stakeholders came to visit the organisation. The volunteer caregivers also complained about the lack of information and support with regard to matters that concerned them. They further felt unsupported by their managers when they raised their concerns, since nobody tried to address or solve these issues. When they needed to express their feelings, they often became discouraged because they knew that it would be in vain. The managers would listen to their issues but do nothing afterwards, which caused a lot of stress for these caregivers. It is crucial for the management of the organisations to improve their communication with the volunteer caregivers, a situation which will be beneficial for the caregivers and the organisations as well as, indirectly, for the patients under their care.

The working environment that the volunteer caregivers found themselves in was often unsupportive yet they were not encouraged to join support groups nor empowered to start their own. The majority of those who participated in the study did not belong to any support groups, which posed a serious challenge for them because they bore all their problems alone until they became depressed and worn out. Asuquo et al. (2013) and Kang'ethe (2011) found that caregivers wished to have support groups to facilitate sharing their difficulties, pains and experiences that caregiving presented to them. This was echoed by the findings of the current study that organisations often do not provide for support groups. Although the volunteer caregivers indicated that they perceived their work as 'mildly' stressful on the Perceived Stress Scale, it is clear from their stories that there are other challenges that threatened their well-being. It would therefore be conducive for the organisations to acknowledge the

challenges faced by these caregivers in their working environment and deal with them effectively. With appropriate support from the organisations, the challenges can be effectively managed and overcome; for example by forming official support groups for caregivers.

Apart from organisational challenges in general, volunteer caregivers further complained about job-related issues that seriously impacted on their ability to do their work sufficiently. Many caregivers in the current study reported that their work was difficult and unsafe due to the lack of necessary materials to do their job, which raised a serious concern about their health. Similar findings had been previously reported by Kang'ethe (2010b) who established that having to take on more responsibilities, along with the shortages or lack of materials, was a serious problem for many of the caregivers. The caregivers in the current study were also concerned that their patients were disadvantaged due to a lack or shortage of basic equipment (such as glucose machines) and a lack of basic resources (such as medicine, soap, disinfectants, bandages and gloves). They believed that these shortages compromised the quality of care that their patients need. This shortage of supplies and resources is often due to inadequate funding of home-based care and contributed to a loss of hope among volunteer caregivers. This serious issue needs the concern and active intervention of organisations and their funders.

A serious challenge to the well-being of caregivers working in the HIV and Aids field is posed by their heavy workload. Akintola et al. (2013) found that the pressure on volunteers to complete their daily work and the exhaustion that comes from the workload, were very serious challenges faced by them. This is corroborated by the findings in the current study where caregivers had a very heavy workload due to the high number of patients they cared for. The caregivers found it very difficult to take care of so many patients, while they also had to take care of their own children at home. The challenges became overwhelming at times resulting in volunteer caregivers neglecting their own self-care with regard to nutrition, exercising, socialising and sleeping, a problem previously identified by Bemelmans et al. (2011). The issue of a heavy workload with too many patients per caregiver calls for serious attention from the managers and the organisations.

Volunteer caregivers who take on too much work with limited resources and support often experience higher levels of stress, which may lead to a loss of concern for patients. Other researchers also commented on this challenge, which often becomes overwhelming for

caregivers, leading to an even lower quality of caregiving (Darling et al., 2010; Kang'ethe, 2010a). This lower quality of service sometimes led to volunteer caregivers being accused by patients and families that they were not doing their jobs properly.

#### **5.4.2 Difficulty with patients**

Caring for people with HIV is often a challenge to the caregivers because they do not get support from the patients. The caregivers' experiences of rejection and blame by patients raised serious concerns in the current study. Some patients displayed anger towards these caregivers by verbally abusing them and demanding that they leave. Some were never satisfied with any assistance given to them by the caregivers. Others also rejected the volunteers' assistance and caused conflicts by making false accusations against them. They complained and blamed the caregivers for being irresponsible, especially when they were in pain. One of the reasons for this rejection and blame by patients is because they feel that the volunteer caregivers do not visit them regularly enough, and because they may feel rejected themselves. Some patients tried to hide their HIV positive status from the neighbours; something that is difficult to do when they are visited by caregivers. Therefore patients may be irritated by these visits. This rejection and bad treatment by their patients became a serious challenge to the volunteer caregivers since they felt that they were already doing more than expected to assist their patients while neglecting themselves and their families in the process. However, they see themselves as the only source of support to some of the patients as the patients' families often do not care (Bemelmans et al., 2011).

Failure by the patients to adhere to their treatment was another challenge experienced by volunteer caregivers. They became frustrated when their patients refused absolutely to take their medication or deliberately postponed collecting their medication from the clinic. Patients would often skip their regular doses of ARVs claiming that the medication made them worse due to the side-effects of these medications. Meiring (2012) and Van Dyk (2010, 2011) similarly established from their studies that non-adherence to antiretroviral medications by patients contributes significantly to caregivers' feelings of helplessness and having no control over the health of their patients.

Volunteer caregivers had to work very hard to support and encourage their patients to follow instructions properly and take their medication as required. They usually encouraged the patients by explaining the benefits of following the instructions; explaining that they would

feel much better if they take their medication consistently. Therefore, in some cases when the patients eventually changed their attitudes, their conditions improved drastically. Organisations should be made aware of volunteer caregivers' frustrations with patients who do not adhere to their medications and provide skills training to volunteers to assist them in coping with this situation; to provide adherence counselling or to cope with a situation where a patient continues with non-adherence.

Another patient-related challenge for many caregivers in the current study is the effects of over-involvement with their patients. Some caregivers formed such a strong bond with their patients and became so close to them that they complicate the caregiver-patient relationship and overstepped the boundaries of duty to assist them. Akintola et al. (2013) also referred to the burden that over-involvement with patients can create. Setting boundaries to protect themselves is therefore very important for volunteer caregivers. The inability to distance themselves from their patients can be a source of extreme stress for them. The stress is also caused by the fact that caregivers often experience a sense of failure and guilt when the patient dies or when there is a deterioration in the patient's health. Caregivers also experienced a sense of powerlessness and helplessness when their patients did not respond to the medication and recover as expected. Volunteer caregivers need to be assisted to develop the skills to distance themselves from their patients when they are off duty.

#### **5.4.3 Difficulty with the patients' family and the community**

Family members of the HIV-infected patient often treated volunteer caregivers badly and often left the whole burden of caring to the caregivers (Ama & Deloilewe, 2011; Coetzee et al., 2011; Kang'ethe, 2011). In some cases, the families were not there for their sick family members and did not care for their well-being at all. Family members further often exploit volunteer caregivers. Apart from their daily responsibilities such as the physical and nursing care of the patient (Akintola et al., 2013), it was often expected from volunteer caregivers in the current study to do additional tasks such as cleaning the house, cooking for the patient and often for the family, doing the shopping, caring for other family members as well as looking after the children. Other researchers (such as Ama & Deloilewe, 2011; Maes, 2012; Mashau & Davhana-Maselesele, 2009) also found that volunteer caregivers are often responsible for much more than what could reasonably be expected from them. This creates a problem for the volunteer caregivers because they had to carry out responsibilities that should not have been expected from them. They often ended up doing household chores instead of

providing proper care for their patients. It is of great concern that the caregiver's job description is often not clear to the patient and the family members.

Families also often showed one or other form of discrimination towards the Aids patient, and this not only affected the sick family member, but also had an adverse effect on the volunteer caregivers. Instead of doing the work they are mandated to do, caregivers now also have to protect the patient against this discrimination and take over family tasks. In the current study, patients would often tell the caregivers that they were obliged to dress their own wounds, bathed themselves and prepared their own food while their prejudiced families gave no assistance at all. A similar lack of support by the family of Aids patients was reported in studies by Ama and Deloilewe (2011), Coetzee et al. (2011) and Kang'ethe (2011) where caregivers expressed being overwhelmed as they were receiving little support from family members or the community at large.

Volunteer caregivers in the current study did not only feel exploited by patients and their family members, they also felt extremely disheartened when the community at large discriminates against them. Some community members humiliated them on the streets, making them feel belittled. It would therefore be conducive for organisations to hold awareness campaigns to assist communities to understand volunteer caregivers and appreciate what they do. Volunteer caregivers further need to be assisted to develop the skills to cope with rejection from the community, should it happen.

#### **5.4.4 Physical and psychological challenges**

Caring for people living with Aids can have a negative effect on the physical as well as the psychological well-being of the caregivers. Volunteer caregivers in the current study often complained of exhaustion and fatigue due to the heavy workloads, not having enough time to rest, and being manipulated and abused by patients. They also suffered from muscular aches and backaches due to lifting of bedridden patients. Ama and Deloilewe (2011) and Jack et al. (2011) also found that caregivers often complained of the physical burden of caregiving. Volunteer caregivers are mostly women and they often do not have the physical strength to do their work. If men (also male family members of the patient) could become involved in caregiving they could reduce this burden by carrying out heavy duties such as lifting or assisting someone who is heavier than themselves. Volunteer caregivers also complained of skin problems and headaches because they were often obliged to walk in the warm sun to

reach their patients' homes. Most of the symptoms that volunteer caregivers complained about in the current study are similar to the ones found by Van Dyk (2012) in her research on the well-being of caregivers.

Apart from the physical challenges, caregivers working in the Aids field often experience psychological and emotional challenges. Caregivers in the current study often felt frustrated, distressed and anxious when they were required to deal with complex clinical aspects of the health of their patients, which had not formed part of their training in home-based care. This challenge was also referred to by other researchers who found that caregivers experienced feelings of anger, depression, frustration and powerlessness due to the deterioration of the physical state of their patients, which they were unable to manage (Ama & Deloilewe, 2011; Mashau & Davhana-Maselesele, 2009). Although volunteer caregivers tried to work hard to assist their patients, they were often discouraged and frustrated by the nursing personnel who were unsupportive. It is a great source of anxiety and distress for them when volunteer caregivers realise that they are alone, with no support from the managers and nursing sisters who are supposed to be their fellow caregivers.

Since some volunteer caregivers are living with HIV themselves, they were also worried about who would care for them when they become sick. Stigma and discrimination was a cause of concern among volunteers living with HIV since they sometimes kept their status a secret from friends and family members (Campbell & Cornish, 2012). Therefore, they present themselves late for treatment or fail to adhere to their medication and become more frustrated and distressed as they start to get sick. A disturbing incongruence noted is that the same volunteer caregivers who experience a lot of stress because their patients do not adhere to their ARV regimen, often cannot themselves adhere to their own ARV regimen.

Fear of infection was another source of anxiety for some of the caregivers in the current study (also see Morwe & Ramaila, 2012 and Ogunmefun et al., 2011). However, most of the volunteer caregivers did not really fear being infected with HIV during the course of their work but were afraid of Tuberculosis infection. The majority of volunteer caregivers revealed that it was very difficult for them to take TB precautions because their patients and some family members did not want them to enter their homes with masks on. When volunteer caregivers provided the family with masks to wear, they simply threw them away when the caregiver was not around due to fear of discrimination from the community.

Volunteer caregivers in the current study also experienced tension when they were challenged by cultural issues that they encountered while doing their job. In many African communities, traditional healers play a very important role in people's health and in their lives. Many of the patients and their families visit traditional healers in addition to formal health care practitioners, causing a serious conflict of interest for the caregivers (Ogunmefun et al., 2011). Some of the patients requested that the volunteer caregiver administer their traditional medicines. This caused a lot of frustration and anxiety for caregivers because, apart from not being trained in doing so, volunteer caregivers are aware of the possible negative interactions between traditional medicines and ARVs. When they refused to perform such treatments, the families and patients began demonstrating some form of negative attitude. Consideration should be given to cultural sensitivities by the organisations and volunteer caregivers in order to provide quality and effective care, without compromising the health of the patient.

#### **5.4.5 Financial challenges**

The economic burden of HIV and Aids should never be underestimated since patients and caregivers need finances to sustain themselves. The issue of financial hardship was another serious challenge mentioned by volunteer caregivers in the current study. There was always a lack of funds for the caregivers and their patients, causing a great deal of anxiety for the caregivers. As noted they often had to wait for months before receiving their stipends, and they often used their meagre income to sustain not only their own families, but also their patients. When they shared their money and food with their patients, it often led to domestic issues, since the caregivers' partners or husbands were displeased with this situation. Patients often expected volunteer caregivers to provide them with food or money from their own pockets, a phenomenon also referred to in the research by Maes, Shifferaw, Hadley and Tesfaye (2010).

The poverty of their patients made caregiving very difficult for the volunteer caregivers who participated in the current study. Even if patients were relatively healthy, they were still very poor and unable to generate an income. Caregivers themselves also do not have time to join other income generating activities due to their demanding job. Due to the nature of their jobs (providing care) they felt sorry for their patients and helped them anyway because they realised the detrimental effect of poor nutrition on the overall recovery of their patients. For example, as mentioned earlier, patients could not take their medications on empty stomachs.



These findings pose very serious questions about ARV distribution programmes which may not achieve their goal if the above challenges are not adequately addressed. Volunteer caregivers are striving for “recovery of the patients” yet the effect of poverty on patients discourages them from doing their job effectively. Morwe and Ramaila (2012) in their study about the situation of caregivers in Thohoyandou in the Limpopo province indicated similar findings. They found that the majority of the caregivers had no income or their earnings were insufficient to provide for them and their patients. Various studies indicated that caregivers become extremely stressed when they do not have money while trying to assist their patients in poverty-stricken communities (Akintola, 2010b; Ama & Deloilewe, 2011; & Kang’ethe, 2010a).

Insufficient funding by government departments and lack of sponsors led to shortages of financial incentives (stipends) for caregivers. Organisations have the challenging task of supporting and meeting the needs of their caregivers. They should regulate or increase the stipends and provide food parcels to patients in order to alleviate the stress encountered by volunteer caregivers on daily basis. That may also motivate the volunteer caregivers to work in the Aids field for a longer period. Although the levels of stress were moderate in the current study, if it is not alleviated or effectively managed, it could result in feelings of not being able to cope, which can lead to caregiver burnout.

## **5.5 COPING MECHANISMS OF VOLUNTEER CAREGIVERS**

According to Lazarus and Folkman (1984), coping constitutes the action taken by individuals when faced with a stressful situation in order to minimise the threat that they are encountering. The majority of the caregivers in the study (45.8%) used emotion-focussed coping strategies such as avoidance of the problem. People often use this kind of coping to maintain hope and optimism, often when individuals believe they are unable to change a stressful situation (Lazarus & Folkman, 1984). Avoidance of the problem has negative side effects because it delays dealing with the problem, as was pointed out by Akintola et al. (2013). Avoiding the problem instead of solving it does not help because the problem “seemed to be solved”, only to surface again at a later time. Volunteer caregivers in the current study who made use of this coping strategy constantly experienced stress due to the lack of more effective coping mechanisms. Some volunteer caregivers said that when they are unable to handle the workload and the problems that they experience, they just ignore it and avoid the situation altogether in order to protect themselves from experiencing stress. This

temporary solution usually works only for a short period of time, until the problem resurfaces.

Problem-solving strategies were used by only 29.2% of volunteer caregivers in the current study. According to Lazarus and Folkman (1984) coping of this nature is used by the individual to identify the cause of the problem who then tries to devise a means of dealing with that particular problem in an effective way. This is by far the most effective coping strategy because it takes care of the problem, and should it resurface in future, the caregiver will be more able to cope with the situation. The manner in which volunteer caregivers in the study tried to solve problems was, for example, to network with colleagues to find new information or advice on how to handle the situation when a patient's condition did not improve. They also did research and read articles to discover more, or they signed up for additional workshops. They also gave more thought to problems and they evaluated both the negative and positive sides of a situation in order to apply new treatments and techniques.

Only 25% of the volunteer caregivers in the study used social support as a coping strategy. Kang'ethe (2011) points out that seeking assistance and support is essential since this can help caregivers to discuss caregiving concerns and be able to encourage one another. Caregivers in the current study who used this coping strategy said that they requested nursing sisters and the management of the organisations to assist them with their problems. Seeking help and support is important because if volunteer caregivers do not receive the necessary support and assistance they will not be able to assist their patients effectively.

These caregivers did not only seek help and support from colleagues, but some also asked for the help of God. Since the beginning of the HIV epidemic, religion has been important in shaping the ways in which individuals, communities and societies responded to the disease (Munoz-Laboy, Garcia, Moon-Howard, Wilson & Parker, 2011). Some of the volunteer caregivers in the current study used prayer as an attempt to come up with solutions to their problems and as a way of dealing with problems associated with stress. Prayer can be an effective strategy because it often changes one's perception of a situation (Root & Van Wyngaard, 2011). Volunteer caregivers expressed their belief that God would hear their cries and change the situation for them when they were incapable of doing so themselves. Caregivers should, according to Garland et al. (2010) focus on meaning-focussed coping as a strategy to cope with challenges where they draw on their beliefs, values and existential goals

to motivate and sustain coping and well-being during difficult times. Many caregivers in the current study are religious, and they should be encouraged to draw strength from this.

Apart from the above-mentioned coping strategies, many volunteer caregivers also mentioned using coping strategies when they were off duty to cope with their stress. For example, they took long walks, listened to music, watched television, played with their children and slept. Some said that they cried a lot and that crying eased their pain.

An interesting finding from the current study, was that caregivers who had a heavier workload, in the sense that they were required to care for more patients, more often used problem solving as well as avoidance as their coping strategies, while those with fewer patients tended to use social support as their coping strategy. The study demonstrated that none of the volunteer caregivers who cared for a low number of patients used problem solving and avoidance of the problem as their coping strategies. One can only speculate on the reasons: Caregivers who have many patients also encounter many challenges that need a practical solution, and if they cannot find this solution, they tend to avoid it altogether. Caregivers with fewer patients may also have more time to communicate with colleagues and friends about their challenges.

If we look at the Transactional Model of stress and coping (Lazarus & Folkman, 1984) as discussed in Chapter 2, the give-and-take transaction between caregiver and patients in the current study does not seem to balance itself out at the end of the caregiving process, since patients and their family members often wanted more from the caregiver than should have been expected from her. The caregiver often ended up being completely exhausted. Managers should organise workshops where caregivers are made aware of the transactional process between them and their patients and the role these transaction play in their way of coping with their work situation. Caregivers should further understand the process of cognitive appraisal, or their personal interpretation of a situation (primary and secondary appraisal according to Lazarus and Folkman, 1984). This will assist caregivers to judge if an event is manageable or challenging and to decide if they have the necessary coping mechanisms and options to handle a situation.

Although the Broaden and Build theory of Johnson et al. (2010) was not directly investigated in this study, caregivers shared many positive experiences and emotions that they derive from caregiving with the researcher. They indicated that these positive emotions are what kept

them going in a very difficult situation. Although the sample was too small to make any significant deductions, there was a tendency for caregivers who experienced their caregiving role as positive to have lower scores on the Perceived Stress Scale, which probably also mean that they have better coping mechanisms. The value of positive emotions in caregiving should not be underestimated and caregivers should be assisted to recognise their own positive feelings and to realise that these emotions can lead to broadened cognitive states – which in the end help them to cope with difficult situations. Caregivers should be encouraged to understand and use the benefits of positive emotions to their own advantage and to build high resilience in stressful situations (Garland, et al., 2010).

Lubkin and Larson (2011) are of the opinion that coping strategies are not inherently good or bad; however, their effectiveness depends on the context in which they are used. Organisations that employ volunteer caregivers should regard themselves as duty bound to empower volunteers with effective coping skills and to encourage them to use strategies which are effective to protect them against stress and burnout. Most of the volunteers who participated in the study used coping strategies that were self-taught and received no assistance from their employers in this regard. The use of ineffective coping strategies impacts negatively on their general well-being (Akintola, 2010a).

Organisations should accord special attention to young volunteer caregivers since in the study they appeared to perceive their job as more stressful than older caregivers did. The reason for this is probably that younger caregivers have not yet developed a way of dealing with problems when they arise and they become more frustrated when their dreams are not fulfilled.

## **5.6 NEEDS OF VOLUNTEER CAREGIVERS AND AVAILABLE RESOURCES**

Volunteer caregivers expressed their different needs and changes that should be made to assist them to do their jobs effectively. Many of their needs correspond with the challenges they expressed (as discussed in Section 5.4). One of the major concerns for caregivers in the study was dissatisfaction with the support provided to them by their organisations. They felt that they did not have enough time to rest and that they would appreciate more leave days. They would also welcome it if the organisations they worked for and the communities they were serving appreciated and respected them more. According to Akintola (2010b) as well as Ama and Deloilewe (2011) rewards and recognition play a major role in sustaining volunteers'

interest in working with home-based care organisations. Organisations should do more to show their appreciation by motivating the volunteer caregivers to see the value of their job and how others are positively impacted when they do their job well. The recovered patients and stakeholders could also be invited to a gathering and all the volunteer caregivers be acknowledged then, for the job well done, in their presence.

Lack of resources is a common concern among caregivers working with patients in the home-care context, especially in resource-poor countries or communities (Akintola et al., 2013). Volunteer caregivers in the current study expressed the need to have access to more resources and materials required to enable them to conduct their daily duties. They felt that the issue of lack of necessary materials could be addressed when the organisations start to prioritise volunteer work. They suggested that organisations may even ask for donations from the community in order to buy the resources, since some of them are not expensive.

Volunteer caregivers were very concerned about the lack of transport. Since home-based care involves visiting patients in their homes, transport should be a priority for organisations and funders. The volunteer caregivers indicated walking long distances to see their patients which jeopardised their proper functioning because they arrived tired at their households. Transport (even if it is only bicycles) could alleviate this stress experienced by caregivers when they do their home visits. Ama and Deloilewe (2011) in their study also indicated that transport is a problem that required immediate attention. Although one of the organisations did have a vehicle, volunteers commented that it would be helpful if the managers could maintain it with enough funds for petrol.

Safety was also a concern for some of the volunteer caregivers. Some felt that their organisation should send them for self-defence training. They also expressed the need for pepper spray (for the purposes of defence) in order for them to be able to walk in their communities without any fear of intimidation or rape by men. The safety of their volunteer caregivers should receive high priority by the organisations they work for.

Remuneration is one of the motivations for volunteer caregivers to continue with their job in the Aids field. Most of the organisations in South Africa rely on unemployed volunteers from affected communities. Usually those volunteers are females who do not receive a salary or who are paid only a small stipend (Akintola, 2011). Volunteer caregivers expressed a need to receive stipends every month instead of waiting for a long period. They felt that the situation

could be changed by fundraising since an increase in stipends and regular payments can improve their personal lives and alleviate daily stress. There is a need to review caregiving policies to make opportunities for incentives that might attract caregivers to remain in their caregiving role.

Volunteer caregivers in the current study felt that their training was not sufficient to offer proper care to their patients. They reported the need for regular capacity building workshops and training based on the common needs of the caregivers. They felt that the organisations they work for should make funds available for them to develop the necessary skills required to do their jobs effectively. If training is considered as an investment, it will empower and equip volunteer caregivers with additional skills, confidence and in some instances opportunities for formal employment (Kang'ethe, 2010a). Training may also assist them to do their jobs properly because they would be able to understand and clearly explain the scope of their practice to the people receiving their services.

Poor communication emerged as another concern requiring attention. Volunteer caregivers in this study expressed the need to talk about their feelings, which they were not given the opportunity to do by their managers. They need to be able to share their concerns with regard to their daily functioning; it appears to be imperative that the management adjusts to this need and gives them a platform to do so. They also desired the necessary skills and opportunity to participate in the decision making processes. Their responses emphasised the urgent need for skills training of both volunteer caregivers and their managers on how to communicate with each other. They indicated that better communication between these role players could only strengthen their relationship, nurture mutual respect and increase a harmonious and effective functioning of the organisation. Penn et al. (2011) agrees that communication skills are an important factor needing careful consideration in organisations. Adequate communications can build a sense of community among volunteers and increase satisfaction through information sharing.

Volunteer caregivers in the study expressed their need for counselling and debriefing sessions in their organisations. They especially needed counselling to help them to cope emotionally with dying and bereaved people. If they receive counselling themselves, they might also be in a better position to help family members and patients to handle their emotional release (Hudson, Thomas, Trauer, Remedios & Clarke, 2011). In the current study, it became apparent that there are limited psychological resources to assist volunteer caregivers; for

example, there are only support groups outside of their organisations. Hence, they often try to give counselling to each other when there is a problem and no professional help is forthcoming. Volunteer caregivers expressed the need for debriefing sessions (either in a small group context or individually) especially after stressful incidents (as was also indicated by Kang'ethe, 2011). The main purpose of the debriefing sessions should be to provide caregivers with a platform to explore their emotions and frustrations in order to cope with the challenges that they face in their daily duties as they care for people living with HIV and Aids. Therefore, organisations should consider counselling and debriefing sessions as something that could empower caregivers and restore confidence and strength, in order for them to continue working successfully in a stressful environment.

Caregivers in this study were not satisfied with the support provided to them by the organisations. It may thus be concluded that they do have specific unmet needs and they want to change the situation in which they find themselves. The intervention of stakeholders is therefore required. Recommendations for caregivers, the organisations they work for, as well as for the Health Department in general are made in the next section.

## **5.7 RECOMMENDATIONS**

The researcher made recommendations that obviously reveal her own interpretations of the information. Therefore, some of the recommendations may not have arisen from the interviews but stem from the researcher's interpretations. However, based on the challenges mentioned above, the following may be made in terms of recommendations for the caregivers, for the managers, for the provincial and national Department of Health and organisations as well as suggestions for future research.

### **5.7.1 Recommendations for caregivers**

It is recommended that caregivers should be encouraged to attend training, especially in home-based care in order to do their jobs properly. The caregivers' lack of knowledge and understanding about some of the side effects of the disease may interfere with their jobs as they would not have been trained to handle certain situations and that might also affect their way of handling the problems they encountered. Caregivers must moreover be encouraged to further their studies, receive training in HIV and Aids care, communication skills,

presentation skills, report writing skills and problem solving skills to improve their knowledge.

Since they complain that their voices are not heard, caregivers should choose one volunteer caregiver to be their representative during their meetings with management. Volunteer caregivers should insist on job descriptions (if these are not in place) and on the strict following of the job description. They should also encourage each other to effectively focus on their specific roles; a task that can be easily achieved since they work in pairs. Adhering to their job description may protect them from getting involved in doing house chores, caring for the elderly and other tasks that are not their responsibility. Another recommendation is that volunteer caregivers should inform the families about their job description from the beginning of their service in order to gain their support and to avoid any misunderstandings.

Since many of the volunteer caregivers did not belong to any support group it is recommended that they negotiate with management to offer such groups for the caregivers. Should this be unsuccessful, caregivers should be encouraged to form their own support groups where they can discuss their issues and encourage each other. They may also start their own initiative such as a “memory box technique” programme, to facilitate the process of grief and bereavement as well as to help them to cope in difficult times.

### **5.7.2 Recommendations for managers**

Unrealistic expectations of volunteer caregivers were revealed as a significant problem in the current study; they often felt exploited by patients, their family members and nursing personnel. It is therefore important for managers in organisations to adopt and maintain a clear job description that is able to be followed by all volunteer caregivers working in the HIV and Aids field. Patients and their family members should also have the job description communicated to them. In addition there appears to be a communication problem between the volunteer caregivers and managers which should be addressed. It is for example, recommended that managers should draw up a weekly plan for all the activities to be done and also adhere to such a plan. Managers should also respect this plan and not call caregivers back for unplanned meetings and so-called emergency situations.

Caregivers clearly needed psychological support; to decrease personnel turnover, managers should provide it. They could for example organise motivational speakers and request



counsellors from outside the workplace to assist with the counselling programmes to empower these volunteers. They may for instance include debriefing and counselling services in their year plan to assist volunteer caregivers every two or three months. It is further recommended that managers should provide the volunteer caregivers with the opportunity to be trained on the effective use of coping strategies. The managers may also arrange with clinic nursing sisters to offer workshops and to train volunteer caregivers about the latest information on HIV and Aids care and support. This may save the organisation the costs of paying for outside training and workshops since organisations often do not have funds to pay for the care of their caregivers. Training should also focus on the relationship between the nursing staff and volunteer caregivers; there is clearly a problem because they do not always get along very well. The managers should encourage the nursing sisters to empower and work together with the volunteer caregivers as they are also assisting the clinics with the out-patients.

To address the issue of over-identification with their patients, the managers should rotate the volunteer caregivers among the patients to avoid bonding and attachment. Volunteer caregivers should be empowered with skills to be able to draw the line between work and personal lives.

The managers should arrange public transport to be available for volunteer caregivers in order to shorten the distance they walk to patients' houses and to enable them to do their job effectively and on time. The managers should also devise, or obtain assistance to devise, income generating projects to maintain the means of transport already available. Such income can also assist to buy umbrellas to use when it is hot and on rainy days.

It is important for caregivers to take time off to rest and energise themselves. It is therefore recommended that managers allocate leave days in their year plan for the caregivers to be given a break and time off to be treated and pampered. They should be informed in time about these leave days so that they can arrange with their working partners and their patients before they leave. Another recommendation is that the managers should develop a plan regarding how to appreciate and reward the volunteer caregivers. Since there are probably insufficient funds in the organisation, they could reward the latter for their hard work with little treats, such as dinners out, soaps and perfumes, and even thank you notes for a job well done, at least until they have more funds.

Managers should do everything in their power to keep volunteer services going. They could for example develop a model that they can use for recruitment, placement and retention of volunteer caregivers. It is however important to select volunteer caregivers very carefully and to find out why they want to volunteer their services. Many volunteers offer their services for selfish purposes (as was also seen in this study) and they may do more harm than good when caring for patients.

### **5.7.3 Recommendations for the Provincial and National Department of Health**

It is recommended that the Department of Health should fund all the NGOs working with HIV and Aids people so that their caregivers can be trained in home-based care. Otherwise, the Department of Health should take the initiative with regard to training all the volunteer caregivers, irrespective of their age, so that they achieve the same level of competency and in this way avoid conflicting roles in the organisations. Another recommendation is that the Department of Health should come up with a clear job description that can be implemented in all home-based care organisations. The researcher further recommends that the Department of Health should develop a model of home-based care that is able to attract men as caregivers as well as professional nurses with specialist training in Aids care to assist the volunteer caregivers.

The Department of Health should be active in advertising its services to the communities and NGOs working with persons living with HIV and Aids in order for community members to understand what caregivers are doing, and also to reduce the intimidation and mockery experienced by caregivers from some community members. It is recommended that the Department of Health should come up with poverty-alleviating plans in the home-based care programmes that can generate income for the volunteer caregivers. It is essential for the Department of Health and organisations to create an environment resulting in the provision of rewards, recognition and incentives to raise the morale and increase the motivation of the volunteer caregivers. Furthermore, it is recommended a model be developed that will incorporate psychosocial support for caregivers of people living with HIV and Aids, including: debriefing, individual and group counselling, respite care, motivational speakers to empower caregivers, coping mechanisms and stress management techniques.

## **5.8 LIMITATIONS OF THE STUDY**

The study was exploratory in nature, and should be seen as laying the foundation for further research into the experiences, challenges and coping mechanisms of volunteer caregivers in the field of HIV and Aids care. The limitations of the study include the following:

- The study focussed on two non-government organisations that deal with HIV and Aids patients. Both NGOs are located in the Gauteng province of South Africa (Tshwane-Soshanguve). Therefore, the results may not be able to be generalised to caregivers outside these organisations, areas and regions.
- The study consisted of a relatively small sample; one organisation had many volunteer caregivers but the number of those who participated in the study was very small; therefore this researcher would not claim that the findings can be generalised to all caregivers in the organisations.
- The organisations and caregivers chosen may not be representative of the current South African caregivers' demographics, which are undergoing change.
- The caregivers were not fluent in English; hence the forms and interview questions were translated into the African language, Setswana which may have impacted the study as the translations might not portray the words accurately.

## **5.9 SUGGESTIONS FOR FUTURE RESEARCH**

It is recommended that further research be conducted in order to explore various ways in which organisations can recognise and support caregivers in their work, even when funding is limited. There should be research on whether the specific caregiver programmes that are available for increasing their resilience and coping are effective. It is also recommended that research be conducted with a larger sample size in order to increase the statistical impact of the study and improve the reliability, validity and generalisation of the research findings. Research should be done on how to develop a model that will assist caregivers and train them on how to cope with their daily experiences of caring for people with HIV and Aids. It is also suggested that research be carried out on how to develop an effective “caring for the caregiver” programme that could be used by all the organisations working with palliative care volunteer caregivers. Since these are the researcher’s suggestions, organisations should only adopt those that might be applicable to their specific contexts.

## **5.10 CONCLUSION**

This study attempted to provide a glimpse into the lives of caregivers who volunteer their services and time to care for people living with HIV and Aids. Although they have many positive experiences, it is clear from the study that they also face many challenges and they are often not respected and appreciated by their managers, nursing personnel, patients and their communities. Africa is absolutely dependent on volunteer caregivers who often carry the brunt of the Aids epidemic. It is therefore extremely important to educate the community, patients and even the organisations they work for, to appreciate the work volunteer caregivers do. Serious attention should therefore be given to the psychological, social and financial wellbeing of volunteer caregivers to retain them to continue doing this very important job.

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## APPENDIX A

### Letter of Request for Permission

1091 Block FF

Soshanguve

0152

Date.....

The Manager

.....

.....

.....

### REQUEST FOR PERMISSION TO CONDUCT RESEARCH AT YOUR ORGANISATION

Dear Sir/Madam

I hereby request permission to conduct research at your organisation with caregivers of people living with HIV and Aids. I am registered for a Master's Degree (HIV and Aids Research - Psychology) at the University of South Africa. The research title is: **The psychosocial challenges and coping mechanisms of palliative care volunteers caring for people living with HIV and Aids.** This study aims to identify the needs and resources available to palliative care volunteers.

Participation is voluntary. No person, group or organisation will be advantaged or disadvantaged in any way by choosing to participate or not participate in the study. Participants will be asked to sign a consent form for their participation in the study.

Furthermore, information will be gathered in the form of individual recorded interviews lasting approximately one hour. All interviews and transcripts will be kept in a safe place to ensure confidentiality, and all identifying information will be excluded in the report. Participants may refuse to answer any questions they feel uncomfortable with and may choose to withdraw from the study at any point should they feel unable to continue participating.

The results of the research will be presented in a report that will be kept at the university. This information may be shared with others in the form of conference presentations and publication in journals. Should you need any further information, please contact me or my supervisor, using the contact details below.

Yours sincerely

.....

Keit Shirinda-Mthombeni

Research – Psychology

0827141434/0124298317

Prof A Van Dyk

Supervisor

0124298514

## APPENDIX B

### Participant Information Sheet

Dear Volunteer Caregiver

My name is Keit Shirinda-Mthombeni; I am registered for a Master's Degree (HIV and Aids Research - Psychology) at the University of South Africa. The research title is: **The psychosocial challenges and coping mechanisms of palliative care volunteers caring for people living with HIV and Aids.** This study aims to identify the needs and resources available to palliative care volunteers. This research will add onto current knowledge about the impact of caregiving among caregivers of people living with HIV and Aids.

Participation is voluntary, and you will not be advantaged or disadvantaged if you choose to or not participate in the study. Your participation will entail an individual interview lasting approximately one to two hours at a time that suits you. The interview will be recorded (audio tape) to ensure accuracy. The recorded information and transcript thereafter will be kept safe in a private locker to ensure privacy and confidentiality. All identifying information will be removed in the research report. On completion of the research, all audio tapes and transcripts will be kept in a locked up place for a period of five years in case anyone would like to verify the authenticity of the research. After this period, the tapes and transcripts will be destroyed completely. Prior to participating you will be asked to sign a consent form, also permission to record the interview and quote some of your responses. You may refuse to answer questions that make you uncomfortable and you may withdraw from the research at any point should you feel unable to continue.

Results of the research will be presented in a report that will be kept in the University library. A copy of the summary of findings with recommendations will be given to the participating organisations. If you wish to participate in the study please indicate in the participant informed consent form and leave the form sealed in the provided envelope with the manager of the organisation.

Yours sincerely

.....

Keit Shirinda-Mthombeni

0827141434/0124298317

## APPENDIX C

### Participant Informed Consent Form

I have read and understood the purpose and procedure of the study. I also agree and promise to keep information shared by others confidential. I have the right to withdraw at anytime, before and during the study. I have been informed that the researcher will be available to answer any questions during the research and I have received her contact details.

I have been given a copy of the participant information sheet.

Name:.....

Age:.....

Contact no:.....

I.....do wish to participate in this study.

.....

.....

Participant's signature

Date:

.....

.....

Researcher's signature

Date:

**Interview date**

**Time**

*Cut here for the participant*.....

*Name*:.....

.....

.....

**Interview date**

**Time**

## APPENDIX D

### Interview & Recording Consent Form

I.....consent to being interviewed by Keit Shirinda-Mthombeni for the research entitled “The psychosocial challenges and coping mechanisms experienced by palliative care volunteers caring for people living with HIV and Aids.”

I understand that participation is voluntary and that:

- I may refuse to answer any uncomfortable questions or withdraw from the study at any point.
- The interview will be recorded and part of my responses may be quoted.
- My responses are confidential and no information identifying me will be included in the research report.

.....

Participant’s signature

.....

Date

.....

Researcher’s signature

.....

Date



## APPENDIX E

### Biographical Questionnaire

Please mark the correct answer below with a tick

#### Personal Information

1. Age      19 – 25   ☐   26 – 30   ☐   31 – 35   ☐   36 – 40   ☐  
                 41 – 45   ☐   46 -50   ☐   51 -55   ☐   56 – 60   ☐   60+   ☐
2. Gender: Male   ☐   Female   ☐
3. Marital status: Single   ☐   Married   ☐   Widow   ☐
4. Educational qualifications  
Primary education   ☐   Secondary education   ☐   Tertiary education   ☐

#### Training & Preparation

5. Did you receive any training in caregiving?: Yes   ☐   No   ☐
6. What type of training? Formal   ☐   Informal   ☐
7. Where did you train?  
.....
8. How long was your training?  
.....
9. In what language did you receive your training?  
English   ☐   Afrikaans   ☐   Other   ☐   Specify.....
10. Are you a member of a support group? Yes   ☐   No   ☐
11. How long have you been with the organisation?  
.....
12. How many patients do you currently have?  
.....

## APPENDIX F

### Semi-Structured Interview Schedule

#### Palliative care volunteers' experiences of their role

What are your daily responsibilities regarding your caregiving role?

What are some of the positive (good) experiences of providing care?

What are some of the negative (bad) experiences you have to face?

How has this role affected your physical & mental health? Indicate with a tick if you have experienced some of these symptoms in the last two months?

- |   |  |
|---|--|
| <input type="checkbox"/> Exhaustion and fatigue | <input type="checkbox"/> Frustration         |
| <input type="checkbox"/> Muscular aches         | <input type="checkbox"/> Anxiety             |
| <input type="checkbox"/> Insomnia               | <input type="checkbox"/> Confusion           |
| <input type="checkbox"/> Headaches              | <input type="checkbox"/> Poor concentration  |
| <input type="checkbox"/> Loss of appetite       | <input type="checkbox"/> Negative attitudes  |
| <input type="checkbox"/> Skin complaints        | <input type="checkbox"/> Resentment          |
| <input type="checkbox"/> Gastrointestinal       | <input type="checkbox"/> dull senses         |
| <input type="checkbox"/> Disturbances           | <input type="checkbox"/> Bad tempered        |
| <input type="checkbox"/> Recurring colds        | <input type="checkbox"/> Shortness of breath |

How has this role affected your relationship with friends and family?

How has this role affected your relationship with colleagues?

#### Reason for volunteering

Why is your role as a volunteer caregiver for HIV/Aids people important to you?

- Your motivations

## **Challenges of palliative care volunteer caregivers/Stressors**

What are the difficulties you face while providing care?

- Work difficulties
- Difficulties with patients

How do your patients feel about you?

Do your patients blame you for some of their problems?

What do you find most stressful about your caregiving role?

## **Coping mechanisms of palliative care volunteer caregivers**

What do you usually do to relieve stress after an especially bad day?

- |   |   |
|---|---|
| <input type="checkbox"/> Talk about the situation         | <input type="checkbox"/> Go to sleep                            |
| <input type="checkbox"/> Take part in physical activities | <input type="checkbox"/> Try to solve a problem                 |
| <input type="checkbox"/> Not doing anything               | <input type="checkbox"/> Try to forget about it                 |
| <input type="checkbox"/> Pray                             | <input type="checkbox"/> Use drugs or alcohol to relieve stress |
| <input type="checkbox"/> Ask for help                     | <input type="checkbox"/> Accept the situation                   |

What do you do to relax? (Calm down)

What kind of support do you receive?

- Inside the organisation
- Outside the organisation

What is your experience of the type of support you get? Are you satisfied or not?

## **Needs of palliative care volunteer caregivers and available resources**

What would you like to change in your organisation that could have a direct effect on your everyday life?

What other support do you think will be beneficial to you?

Is there anything else you feel is important to mention?

*Thank you for your time*

## APPENDIX G

### Perceived Stress Scale (PSS)

The questions in this scale ask you about your feelings and thoughts during the last month. In each case, you will be asked to indicate by circling how often you felt or thought a certain way.

Please circle the best suited option according to this scale:

- 0 = Never
- 1 = Almost Never
- 2 = Sometimes
- 3 = Fairly Often
- 4 = Very Often

QUESTIONS PERTAIN TO HOW YOU FELT/THOUGHT IN YOUR JOB CAPACITY

1. In the last month, how often have you been upset  
because of something that happened unexpectedly? ..... 0 1 2 3 4
  
2. In the last month, how often have you felt that you were  
unable to control the important things in your life? ..... 0 1 2 3 4
  
3. In the last month, how often have you felt nervous  
and “stressed”? ..... 0 1 2 3 4

4. In the last month, how often have you felt confident about  
your ability to handle personal problems that originated  
due to your job? ..... 0 1 2 3 4
5. In the last month, how often have you felt that things  
were going your way?..... 0 1 2 3 4
6. In the last month, how often have you found that you  
could not cope with all the things that you had to do?..... 0 1 2 3 4
7. In the last month, how often have you been able  
to control irritations in your life?..... 0 1 2 3 4
8. In the last month, how often have you felt that you  
were on top of things?..... 0 1 2 3 4
9. In the last month, how often have you been angered  
because of things that were outside of your control?..... 0 1 2 3 4
10. In the last month, how often have you felt difficulties were  
piling up so high that you could not overcome them? ..... 0 1 2 3 4

*Note.* From “A global measure of perceived stress,” by S. Cohen, T. Kamarck and R. Mermelstein, 1983, A global measure of perceived stress, 21, p. 386-396.

## APPENDIX H

Questionnaire No:-\_\_\_\_\_

Date:\_\_\_\_\_

### COPING STRATEGY INDICATOR

We are interested in how people cope with the problems and troubles in their lives.

Listed below are several possible ways of coping. We would like you to indicate to what extent you, yourself, used each of these coping methods. All of your responses will remain anonymous.

Try to think of one problem you have encountered in the last six months or so. This should be a problem that was important to you, and that caused you to worry (anything from the loss of a loved one to an accident, but one that was important to you).

Please describe this problem in a few words (remember, your answer will be kept anonymous):

---

With this problem in mind, indicate how you coped by checking the appropriate box for each coping behaviour listed on the following pages. Answer each and every question even though some may sound similar.

Did you remember to write down your problem? If not please do so before going on.

Keeping that stressful event in mind, indicate to what extent you ....

1. Let your feelings out to a friend? ☐ A lot ☐ A little ☐ Not at all
2. Rearranged things around you so that  
your problem had the best chance of being  
resolved? ☐ A lot ☐ A little ☐ Not at all
3. Brainstormed all possible solutions before  
deciding what to do? ☐ A lot ☐ A little ☐ Not at all
4. Tried to distract yourself from the problem? ☐ A lot ☐ A little ☐ Not at all
5. Accepted sympathy and understanding from  
someone? ☐ A lot ☐ A little ☐ Not at all
6. Did all you could to keep others from seeing  
how bad things really are? ☐ A lot ☐ A little ☐ Not at all
7. Talked to people about the situation because  
talking about it helped you to feel better? ☐ A lot ☐ A little ☐ Not at all
8. Set some goals for yourself to deal with the situation? ☐ A lot ☐ A little ☐ Not at all
9. Weighed your options very carefully? ☐ A lot ☐ A little ☐ Not at all
10. Daydreamed about better times? ☐ A lot ☐ A little ☐ Not at all
11. Tried different ways to solve the problem  
until you found one that worked? ☐ A lot ☐ A little ☐ Not at all
12. Confided your fears and worries to a friend  
or relative? ☐ A lot ☐ A little ☐ Not at all
13. Spent more time than usual alone? ☐ A lot ☐ A little ☐ Not at all
14. Told people about the situation because just  
talking about it helped you to come up with

solutions?

15. Thought about what needed to be done to  
straighten things out? ☐ A lot ☐ A little ☐ Not at all
16. Turned your full attention to solving the problem? ☐ A lot ☐ A little ☐ Not at all
17. Formed a plan of action in your mind? ☐ A lot ☐ A little ☐ Not at all
18. Watched television more than usual? ☐ A lot ☐ A little ☐ Not at all
19. Went to someone (friend or professional) in  
order to help you feel better? ☐ A lot ☐ A little ☐ Not at all
20. Stood firm and fought for what you wanted in  
the situation? ☐ A lot ☐ A little ☐ Not at all
21. Avoided being with people in general? ☐ A lot ☐ A little ☐ Not at all
22. Buried yourself in a hobby or sports activity  
to avoid the problem? ☐ A lot ☐ A little ☐ Not at all
23. Went to friend to help you feel better about  
the problem? ☐ A lot ☐ A little ☐ Not at all
24. Went to a friend for advice on how to change  
the situation? ☐ A lot ☐ A little ☐ Not at all
25. Accepted sympathy and understanding from  
friends who had the same problem? ☐ A lot ☐ A little ☐ Not at all
26. Slept more than usual? ☐ A lot ☐ A little ☐ Not at all
27. Fantasised about how things could have  
been different? ☐ A lot ☐ A little ☐ Not at all
28. Identified with characters in novels or movies? ☐ A lot ☐ A little ☐ Not at all



29. Tried to solve the problem? ☐ A lot ☐ A little ☐ Not at all
30. Wished that people would just leave you alone? ☐ A lot ☐ A little ☐ Not at all
31. Accepted help from a friend or relative? ☐ A lot ☐ A little ☐ Not at all
32. Sought reassurance from those who know  
you best? ☐ A lot ☐ A little ☐ Not at all
33. Tried to carefully plan a course of action rather  
than acting on impulse? ☐ A lot ☐ A little ☐ Not at all

*Note.* From “A Factor Analytically Derived Measure of Coping: The Coping Strategy Indicator,” by Amirkhan J.H. (1990), *Journal of Personality and Social Psychology* 1990, Vol 59, No. 5, p.1066-1074

**You may STOP here.**

**Thank you for your cooperation.**

## APPENDIX I

### SCORING INSTRUCTIONS

- For each response, assign a numerical score:

If the response is **A lot**, assign a score of **3**.

If the response is **A little**, assign a score of **2**.

If the response is **Not at all**, assign a score of **1**.

- Enter the scores for each question in the appropriate column below:

| SCALE I         |       | SCALE II         |       | SCALE III         |       |
|-----------------|-------|------------------|-------|-------------------|-------|
| Item            | Score | Item             | Score | Item              | Score |
| #2              | _____ | #1               | _____ | #4                | _____ |
| #3              | _____ | #5               | _____ | #6                | _____ |
| #8              | _____ | #7               | _____ | #10               | _____ |
| #9              | _____ | #12              | _____ | #13               | _____ |
| #11             | _____ | #14              | _____ | #18               | _____ |
| #15             | _____ | #19              | _____ | #21               | _____ |
| #16             | _____ | #23              | _____ | #22               | _____ |
| #17             | _____ | #24              | _____ | #26               | _____ |
| #20             | _____ | #25              | _____ | #27               | _____ |
| #29             | _____ | #31              | _____ | #28               | _____ |
| #33             | _____ | #32              | _____ | #30               | _____ |
| Total I = _____ |       | Total II = _____ |       | Total III = _____ |       |

- Sum each column, and enter the totals in the appropriate boxes on the graph below.

- Mark each bar of the graph below at the point indicated by each column total. Fill in the bar up to that point to graphically indicate preferred coping strategy.

